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Offenders with Intellectual Disabilities: An Exploration of Prevalence and Transitional Care Experiences

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THESIS CONTENT AND FORMAT

The current thesis portfolio contains two separate chapters; a systematic literature review and an empirical research project. The focus of the empirical project was to explore the transitionary experiences of offenders with intellectual disabilities, using a qualitative approach. This project focused on offenders' transitions from secure hospital settings to community rehabilitative placements.

Due to the sparsity of literature investigating transition outcomes for this specific forensic population it was not feasible to conduct a systematic literature review on this topic. The focus of the current systematic review was the prevalence of prisoners with intellectual disabilities within the UK prison population. The alternative systematic review topic was identified because the issues in establishing prevalence of intellectual disabilities in the Criminal Justice System are closely linked to transitionary experiences and service development in both secure hospital settings and community services.

A Note on Terminology

The current thesis portfolio employs the term '*Intellectual Disability',* as this is the terminology most frequently employed in research. This is also the terminology employed within the selected journal: *Journal of Applied Research in Intellectual Disabilities*.

The author recognises that the term '*Learning Disability'* is more commonly employed in clinical practice in the United Kingdom.

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THESIS ABSTRACT

Background

Offenders with Intellectual Disabilities (ID) represent a particularly vulnerable population within Criminal Justice System. Uncertainty remains in relation to the proportion of prisoners with intellectual disabilities within the UK. This presents challenges in service provision and development across both custodial and secure settings. Concurrent reforms in legislative practice and developments in models of offending behaviour have resulted in a development of community-based services for offenders with intellectual disability. Provision of good quality transitionary care for this population presents remains challenging and there is an increasing need to develop a more collaborative and person-centred measure of the '*successfulness*' of these transitions.

Methodology

A systematic review was completed regarding the prevalence of ID in UK prisons and methodological quality was explored. This aimed to inform research, professional practice and service development. An empirical study employed the qualitative methodology of Interpretative Phenomenological Analysis to explore the transitionary experiences of offenders with ID across secure settings. This was aimed to address gaps in the existing literature and address over-dependence on traditional post-transition outcome measures.

Results

Systematic review findings demonstrated ID prevalence rates between 0% - 8.5% of the UK prison population. Studies were found to be of moderately low methodological quality and results must be interpreted with caution. Empirical study findings identified five master

themes in relation to transitionary experience: Relationships with Staff, Lived Experience of Transition, Steps towards Freedom, Community Embeddedness and Different Concepts of Self.

Conclusions

Suggestions are provided for future research in relation to the need for more accurate estimates of ID prevalence in UK prisons with better adherence to standard diagnostic criteria for ID. The importance of screening for intellectual disabilities in prison populations is discussed and implications for professional practice are considered. In relation to the empirical study suggestions are provided for future research in relation to active participation of individuals with intellectual disabilities. The importance of employing newer models of offending behaviour in professional practice is considered.

CHAPTER 1. SYSTEMATIC LITERATURE REVIEW

The Prevalence of Intellectual Disabilities among UK Prisoners: A Systematic Review

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1.1 ABSTRACT

Background

Uncertainty remains in relation to the proportion of prisoners with intellectual disabilities within the UK. The aim of the current review is to identify, to summarise results of and to critically appraise the methodological quality of the studies investigating the prevalence of intellectual disability in UK prisons.

Methodology

A systematic search of four databases was supplemented by searches of government publication databases and other sources outlined. Methodological quality was assessed through the use of Munn's Critical Appraisal Instrument.

Results

Ten studies were included in the final review. Reported prevalence rates of prisoners with intellectual disabilities ranged between 0% - 8.5% of the general UK prison population. Use of an established critical appraisal instrument indicated that all of the included studies were of moderately low methodological quality. Overrepresentation of intellectual disabilities must be interpreted in the context of poor adherence to standardised diagnostic criteria in the identified literature.

Conclusions

Suggestions are provided for future research in relation to the need for more accurate estimates of prevalence and development of screening measures. The importance of screening for intellectual disabilities in prison populations is discussed and implications for professional practice are considered.

Keywords: Prisoners, prisons, forensic, criminal justice, intellectual disabilities, prevalence.

1.2 INTRODUCTION

There continues to be uncertainty about the proportion of prisoners with intellectual disabilities within the United Kingdom (UK) (Loucks, 2007). Large scale prison studies investigating the prevalence of intellectual disabilities amongst prisoners have varied markedly in their estimates. Results from these studies report intellectual disability prevalence rates ranging from less than 1% of the UK prison population (Gunn *et al*., 1991) through to an estimated 28% of the prison population (Murphy *et al*., 2000). More recent UK studies have reported intellectual disability prevalence rates as around 7% of the prison population, with over one quarter of the prison population falling within the borderline range of intellectual functioning (Hayes, 2007).

Fazel *et al*. (2008) completed a systematic review examining the prevalence of prisoners with intellectual disabilities within international prison populations. Results of the ten studies included highlighted intellectual disability prevalence rates ranging between 0% of the prison population sampled in New Zealand (Brandford, 1997) to 2.9% of the prison population sampled in Dubai (Ghubash, 1997). Caution must be exercised when synthesising results of international studies due to the significant differences between healthcare and Criminal Justice Systems between countries, including vast differences between diversionary policy and practice for offenders with intellectual disabilities, at various stages in their journey through the Criminal Justice System. Additionally, there are further complications in comparing results between countries due to differing constructs and diagnostic classifications of intellectual disabilities (Jones, 2007). Despite the variance in both UK and international

studies, there is certitude around the importance of identifying prisoners with intellectual disabilities.

1.2.1 Importance of Identification of Intellectual Disabilities in Prison Populations

In consideration of the needs of individuals with an intellectual disability within the general population, studies have suggested that there are higher rates of psychiatric co-morbidity amongst people with intellectual disabilities in comparison to the general population as a whole (Cooper *et al*., 2007; Deb *at al*., 2001). In addition to the differing profile of mental health needs there is also an increased likelihood of these needs not being met as a result of the well evidenced problem of diagnostic overshadowing (Mason & Scior, 2004). In view of the increased likelihood of comorbidities and diagnostic overshadowing for individuals with intellectual disabilities it is even more essential that rigorous screening and assessment be implemented.

Furthermore, within the general prison population, there is also a higher prevalence of psychiatric disorders in comparison with general population (Singleton *et al*., 1998; Singleton *et al*., 2001). There is also evidence that prison leads to a worsening of pre-existing mental health problems (Joint Committee on Human Rights, 2004). Despite a downward trend in the number of suicides in prisons, there remains a higher prevalence of suicide, in comparison with the general population (Shaw *et al*., 2013). Additionally, there is poorer recognition of mental health needs and therefore inequity of access to appropriate treatment and/ or

individual risk assessment in comparison with the general population (Birmingham *et al*., 1996). Consequently, prisoners represent a population who experience many health and social inequalities (Shaw, 2003) and experience higher levels of unmet mental health need (Harty *et al*., 2003). This is notably similar to individuals with intellectual disabilities, resulting in prisoners and with an intellectual disability representing a doubly marginalised population, which are individually and systematically disadvantaged within the prison system (Talbot, 2008).

1.2.2 Individual Level Aspects of Identification

When considering the importance of identification of prisoners with intellectual disabilities, at an individual level, Talbot (2008) highlights that failure to identify can lead to increased risk and associated vulnerability. This vulnerability relates to potential difficulties in adapting to the prison environment and coping with increased communicative and social demands (Loucks, 2007). Identification is essential in meeting physical health needs, as prisoners with intellectual disabilities are more likely to have poorer health outcomes (Dias *et al*., 2013). Identification is also key in meeting other needs of individuals with intellectual disabilities including social, psychological, educational and occupational needs (Lindsay *et al*., 2004) and to facilitate associated care planning (Joint Inspection by HMI Probation and HMI Prisons Report, 2015).

Failure to identify prisoners with intellectual disabilities has lead to direct contravention of the Disability Discrimination Act (2005). This is due to the subsequent barriers in accessing

appropriate support, skills training programmes (Barron *et al*., 2002) and barriers in accessing appropriately adapted rehabilitative treatment programmes facilitated within prisons (Herrington *et al*., 2005). The Joint Committee on Human Rights (2008) reported that this has lead to prisoners with an intellectual disability serving longer custodial sentences in comparison with neuro-typical prisoners convicted of similar offences. A recent example of this is demonstrated in the well-documented case of Mr. Dennis Gill, for whom the inability to access appropriate offending behaviour programmes resulted in considerable delay in his release from prison. This was found to be in contravention of the aforementioned disability discrimination legislation (McArdle, 2010).

1.2.3 Public Protection Level Aspects of Identification

At a public protection level, there is a need to identify prisoners with intellectual disabilities in order to inform formulation of offending behaviour and to inform structured risk assessment and subsequent risk monitoring and management (Lindsay *et al*., 2004). Failure to identify prisoners with intellectual disabilities results in a systemic failure to recognise the requirement for close interagency working and consequently a lack of support from the appropriate professionals (Myers, 2004). Poor identification of intellectual disabilities within the prison may also lead to an increased risk of reoffending, due to unmet needs and lack of associated support and services (Loucks, 2007; Loveland & Boyle, 2007).

1.2.4 Service Development Level Aspects of Identification

Finally, at a service level there is a clear need for effective identification of prisoners with intellectual disabilities. Accurate prison prevalence data is required in ascertaining levels of need and informing service provision and development (Bradley Report, 2009). The aforementioned lack of clarity in reported intellectual disability prevalence rates in UK prisons has resulted in overdependence upon international research. This has resulted in challenges in the accurate prediction of need, and challenges in the development and provision of services at various stages in the UK Criminal Justice System (Badger *et al*., 1999). The '*gaps*' in appropriate services for offenders with intellectual disabilities are well documented at various stages within the Criminal Justice System including transitions from custodial environments (Pearsall *et al.,* 2014).

1.2.5 Diagnostic & Classification Issues in Prevalence Literature

In consideration of the research investigating the prevalence of prisoners with intellectual disabilities, there are multiple issues that may have contributed towards the significant variance reported. Firstly, classification problems persist in relation to the diagnostic definition of intellectual disability and the range of terminology employed is likely to have further added to the uncertainty around the prevalence of offenders with intellectual disabilities in the wider Criminal Justice System (Holland *et al*., 2002). With regard to the standard diagnostic criteria, it is generally accepted that for an individual to be diagnosed with an intellectual disability there should be*: i)* significant impairment of intellectual functioning (evidenced by an Intelligence Quotient (IQ) < 70), *ii)* significant impairment of

adaptive/ social functioning and *iii)* evidence of the onset of these difficulties prior to the age of 18 years (British Psychological Society, 2001; ICD-10: World Health Organisation, 1992).

With regard to the clinical assessment of the above diagnostic criteria, the most widely accepted assessment measure of intellectual functioning is the Wechsler Adult Intelligence Scales (WAIS-IV; Wechsler, 2008). This standardised, individually administered assessment of intellectual functioning provides an overall full-scale IQ (FSIQ) and a measurement of intellectual functioning across four distinct indices. The most commonly used measures of adaptive functioning include the Adaptive Behaviour Assessment System (ABAS; Third Edition – Harrison & Oakland, 2015) and the Vineland Adaptive Behaviour Scales (VABS; Second Edition - Sparrow *et al.,* 2005). Both the ABAS-III and the VABS-II measure adaptive functioning across a number of different domains and are typically completed by parents/ caregivers, with a self-rating option for adults within the ABAS-III.

In order to improve identification, a number of intellectual disability screening tools have also been developed including the Learning Disability Screening Questionnaire (LDSQ; McKenzie & Paxton, 2006). This screening measure had been standardised within a small forensic sample (McKenzie *et al.* 2012), demonstrating both sensitivity and specificity > 80%. Additionally screening measures specifically designed for use with forensic populations include the Learning Disabilities in the Probation Service Scale (LIPS; Mason & Murphy, 2002b) and the Hayes Ability Screening Index (HASI; Hayes, 2000). However, there is evidence that some screening measures may be over-inclusive (Mason & Murphy, 2002b).

Despite the development of these screening measures there is not one screening tool that is widely accepted as a '*gold-standard'* in the identification of intellectual disabilities (Loucks, 2007).

When examining studies that utilise IQ as a single indicator, it is noted that the variation in IQ cut-offs employed can result in significantly different intellectual disability prevalence rates being reported (Hayes *et al.*, 2007). Additionally, McBrien (2003) highlighted that the vast majority of studies investigating the prevalence of intellectual disabilities in prison populations fail to evidence the three diagnostic criteria being met through the above assessment measures. Very few studies include a measure of IQ *and* adaptive functioning *and/or* the age of onset of difficulties (Mason & Murphy, 2002b; Mottram, 2007). As well as a risk of assuming that an IQ < 70 is, in itself, sufficient, this also means that prisoners with intellectual impairment as a result of traumatic and/or acquired brain injuries sustained after the age of 18 years could be included erroneously in the reported intellectual disability prevalence rates. Lack of access to developmental information is one of the inherent challenges in assessing imprisoned individuals; however, historical case note review and detailed clinical interview could be employed to supplement information obtained via direct standardised assessment.

Similarly, there are inherent challenges in the assessment of social/ adaptive function in prison populations. As with obtaining information in relation to the age of onset of difficulties, these challenges include lack of access to information that might be obtained through historical case

note review or interview with parents/caregivers or other family members. Additionally, Murphy *et al.* (2015) highlight that the very nature of the prison environment means it is difficult for prisoners to engage in their '*typical*' range of adaptive behaviours. This has resulted in the neglect of a measurement of current adaptive functioning (The Bradley Report, 2009) and over-dependence upon more rudimentary screening measures such as basic self-reporting checklists (Murphy *et al*., 1995). Arguably self-report measures can be difficult to access and understand for individuals with intellectual disabilities and this could result in under-identification of intellectual disabilities and/ or psychiatric comorbidities. Historically, there has also been reliance on screening information relating to educational placement (Mason & Murphy, 2002a), which will become increasingly unreliable as a result of the mainstream inclusion movement.

It is recognised that obtaining information in relation to pre-imprisonment adaptive functioning information would be challenging and may be limited by budgetary and time constraints. Despite this, it is important to acknowledge that this information is not entirely unattainable. It is reasonable to suggest that measures of adaptive functioning could be administered with parents/ caregivers, other family members or via self-rating, where appropriate. Attaining closer adherence to the current diagnostic criteria employed clinically, with the general population, would ensure greater efficacy of intellectual disability prevalence data obtained from prison populations and allow for more meaningful comparisons.

1.2.6 Methodological Issues in Prevalence Literature

In addition, methodological problems include the type and reliability of the screening measures employed. Some studies have employed self-report items in initial screening measures (Murphy *et al*., 1995) and the vast divergence in sampling methods has contributed to confusion regarding correct prevalence rates (Simpson & Hogg, 2001; Lunsky *et al*., 2011). The type, reliability and timing of administration of cognitive assessment measures also appears to contribute to variability in prevalence data (Loucks, 2007). Noble and Conley (1992) observed that estimated IQ scores tended to be lower among individuals assessed shortly after entering prisons and among individuals assessed using an IQ measure other than a validated measure of intellectual functioning such as the Wechsler Adult Intelligence Scales. Other studies have failed to employ direct assessment measures and have relied upon retrospective case note review and staff interview in order to estimate prevalence (Department of Health, 1998). Despite the recognition of the lack of studies employing appropriate measures this does not appear to have changed significantly (Uzieblo *et al*., 2012).

1.2.7. Rationale - Systematic Literature Review Aims

In consideration of the importance of identification and variance between studies investigating the prevalence of prisoners with intellectual disabilities, the aim of the current systematic review is to identify, to summarise the results of and to critically appraise the methodological quality of the available literature investigating the prevalence of prisoners with intellectual disabilities within the UK prison populations. It is hoped that this will further inform research, professional and practice and policy from an individual level through to a service development level.

1.3 METHODOLOGY

1.3.1 Information Sources and Literature Search Strategy

A systematic search of literature was conducted across four electronic databases: PsycINFO (Jan 1955 to July Week 1 2015), EMBASE (1974 to Week 7 2015), OvidMEDLINE (R) (Jan 1955 to July Week 1 2015) and CINAHL Plus (Jan 1955 – July 2015). Studies were limited to those published in English. Other limits included human-only studies of adults (16+yrs). Multi-database searches were conducted across multiple-purpose fields including titles, abstracts, subject headings and keywords. A combination of keyword search terms was employed: (prison* or imprisoned or offend* or jail* or detain* or felon or incarcerat* or custod* or inmate* or correctional or criminal* or penal or sentenc*) and (disab* or intellectual* or "intellectual development" or developmental* or learning or retard*) and (prevalence or incidence). The literature search was supplemented by searching other relevant sources including the Electronic Theses Online Service (EThOS), the Prison Reform Trust (PRT), the Bromley Trust, the Offender Health Research Network, the Scottish Centre for Crime & Justice Research (SCCJR), the Scottish Prison Service (SPS) and the Scottish Government Publications Repository. The Home Office Publications Repository was also searched which included literature from HM Prison Service, HM Inspectorate of Prisons, HM Inspectorate of Probation, National Offender Management Service (NOMS) and the Ministry of Justice (MoJ). Reference lists of included studies were also searched for other relevant papers.

1.3.2 Data Extraction and Analysis

The initial database literature and supplemental searches identified a total of 683 studies. Following deduplication, references were screened and then selected or removed through an iterative approach. During this process study inclusion and exclusion criteria, (as outlined in *Table 1*. below), were systematically applied to the literature and studies were screened for suitability at title and then at abstract stage. Following this, the remaining 43 studies were reviewed in full and a further 33 studies were removed at this stage. See *Appendix 2*. for full list of studies and reasons for exclusion. The remaining 10 studies were assessed for methodological quality within the current review. See *Figure 1*. below for full outline of systematic search and study selection process.

Table 1. *Study Inclusion and Exclusion Criteria*

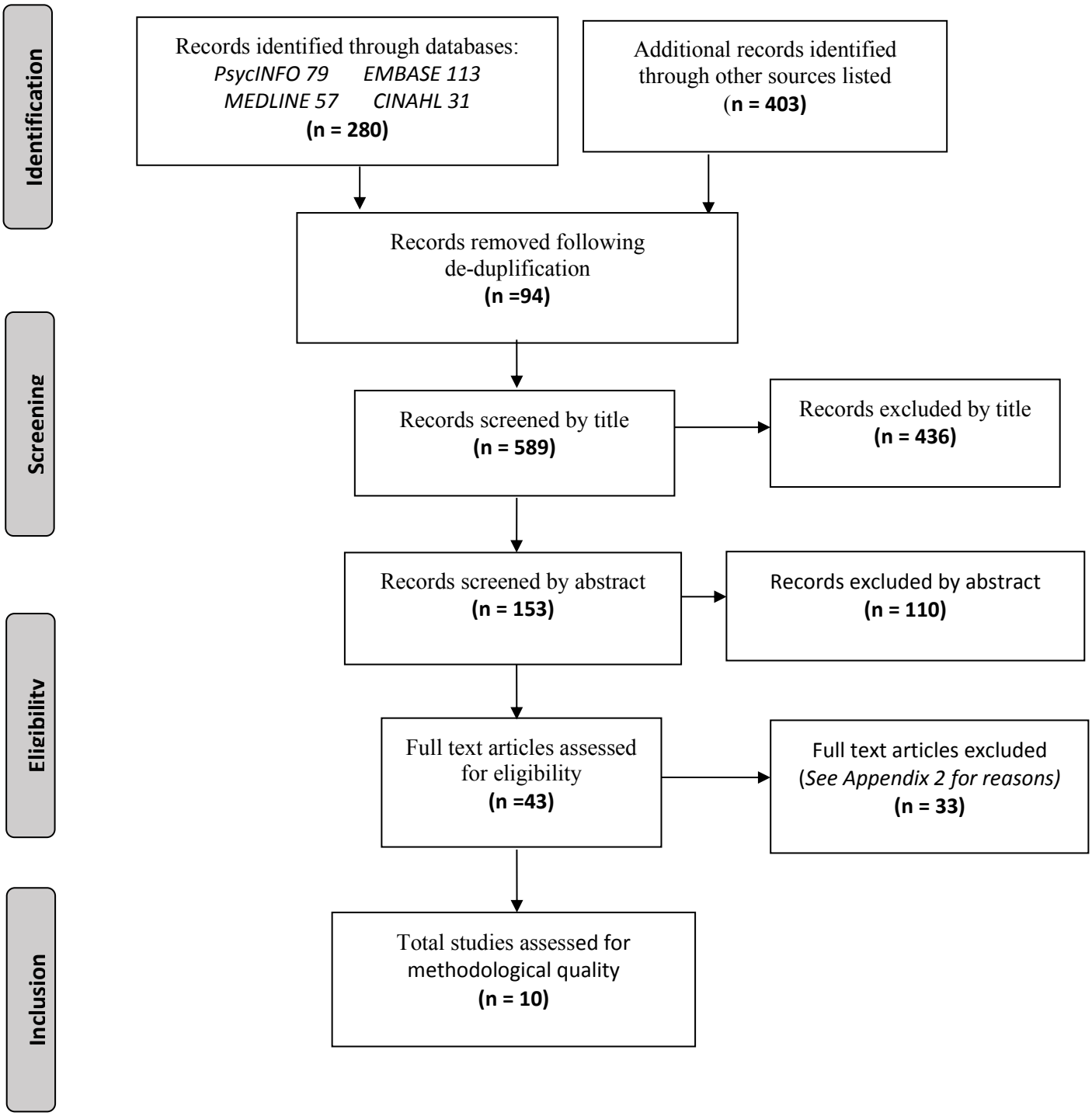
Inclusion Criteria
1. Studies undertaken within UK prisons with both remand and sentenced prisoners
2. Empirical studies that present quantitative data on the prevalence of ID
3. Studies that utilise a representative or random sample of prisoners
4. Studies that primarily examine adult prisoners aged 16-90 years
5. Studies that employed validated measures for assessing or screening IQ and/or expert clinical examination (on an individual basis) and/ or a validated measure of adaptive functioning and/or a validated intellectual disability screening measure
Exclusion Criteria
1. Studies that solely investigated, or included that data on other forensic populations e.g. secure inpatient populations or probation populations in samples (without clear differentiation in the reported data)
2. Studies that solely assessed for, or included data on the presence of specific learning difficulties i.e. dyslexia in samples (without clear differentiation in the reported data)
3. Studies that only reported findings on young offenders i.e. only between 16-21 years

Although the present review aimed to employ the aforementioned diagnostic criteria for ID, during the preliminary literature searching it was recognised that many of the UK prison prevalence literature failed to evidence all three criteria being met. The inclusion of such studies is reflected upon later in this review.

Prior to assessment of methodological quality, systematic data extraction was completed by the lead author. For the purposes of the current review the following data was extracted: year of publication, study location, gender of participants, mean age of participants, prisoner status, total sample size, initial screening procedure, final diagnostic tool(s) employed, interviewer/ clinician completing assessment, total number or participants diagnosed with an intellectual disability and percentage of participants diagnosed with an intellectual disability.

Figure 1. *Systematic Literature Search and Study Selection Process*

N.B. Flow diagram adapted from Prisma Diagram by Moher *et al*. (The PRISMA Group, 2009).



1.3.3 Assessment of Methodological Quality

Methodological quality was assessed through use of the critical appraisal instrument developed by Munn *et al.* (2014). See *Appendix 3*. Prevalence Critical Appraisal Instrument. The design of this tool was informed by the structure and content of other pre-existing critical appraisal instruments, including but not limited to, the Joanna Briggs Institute (2014), the Centre for Evidence-Based Management Critical Appraisal of a Survey (2014) and a previous critical appraisal instrument specifically developed to assess the methodological quality of prevalence research (Loney *et al.*, 1998). A strength of this particular critical appraisal instrument is the inclusion of criterion in relation to both internal validity of studies (i.e. *were participants recruited in an appropriate way*?) and external validity of studies (i.e. *was the sample representative of the target population*?).

Included studies were rated across ten criteria including representativeness and size of sample, appropriateness of recruitment, coverage of data analysis and accuracy of measurement of the condition studied. Additional comments have been added to each of the ten criteria for guidance in relation to the particular clinical population investigated (prisoners with intellectual disabilities) and in relation to the specific aims of the current review, see *Appendix 3*. for further information.

All included studies were initially rated by the lead author. Following this half of the included studies (n= 5 of 10) were co-rated by a second author. Co-rater reliability was assessed through

use of Cohen's Kappa statistic, which demonstrated substantial agreement between raters: Kappa = .896 (95%). Any discrepancies were resolved through discussion.

1.4 RESULTS

1.4.1 Study Characteristics & Demographic Information

Characteristics and demographic information from the ten included studies are summarised in *Table 2*. below. Studies are presented and numbered in chronological order and for the sake of brevity will be referred to as S1- S10. Studies ranged in date of publication from a large-scale study published in 1991 (S10) through to the most current study published in 2015 (S1). The vast majority of studies (n= 9 of 10) collected prevalence data from England (S1, S2, S3, S5, S6, S7, S8, S9, S10), a further four studies also collected data from Wales (S5, S7, S9, S10), while only one study reviewed had collected data from Scotland (S4).

In relation to gender of samples, five studies sampled only male prisoners (S1, S2, S4, S6, S8), four studies sampled both male and female prisoners (S3, S5, S7, S10) and only one study sampled only female prisoners (S9). There was clear homogeneity of mean age of samples observed, with mean ages ranging from 26 years (S10) through to 33 years (S2, S3). A total of five studies included only sentenced prisoner samples (S1, S2, S6, S9, S10), three studies included only remand prisoner samples (S6, S7, S8,) and a further three studies included both remand and sentenced prisoners samples (S3, S4, S5). Studies differed significantly by sample

size with one study reporting a modest sample size of 88 participants (S4), through to much larger scale studies reporting samples sizes in excess of 2000 participants (S1, S5, S10).

There was substantial variation in the types of measures employed in screening for intellectual disabilities. Seven studies employed some form of initial screening measures (S1, S3, S4, S5, S6, S7, S8), ranging from formalised, standardised measures including the LDSQ, HASI or IQ Quick Test (S1, S3, S4, S5, S6, S7) through to the use of more rudimentary screening procedures such as non-standardised functional questionnaires (S8). Two of these studies relied solely on screening measures as diagnostic tools in order to *estimate* prevalence of intellectual disabilities (S1, S5).

There was also substantial variation observed in relation to the diagnostic assessment measures employed to assess for intellectual disabilities. The significant majority (n= 5 of 6) of studies conducted before 2005 relied solely upon basic screening measures, clinical interview and case note review (S5, S6, S7, S9, S10) with only one study employing a standardised measure of intellectual functioning (S8). More recent studies investigating the prevalence of intellectual disabilities in prison populations have attempted to include standardised measures of intellectual functioning such as the WAIS-III (S4, S3, S2) with two of these more recent studies also including a standardised measure of adaptive functioning such as the VABS questionnaires (S3, S2).

1.4.2. Reported Prevalence Rates

From the ten studies included there was some variation within reported rates of prevalence of prisoners with intellectual disabilities within the general prison population. Prevalence rates ranged from 0% of the general prison population (S8) through to 8.5% of the general prison population (S5). The majority (n= 7 of 10) of the ten studies reported prevalence rates of <3% of the general prison population (S2, S4, S6, S7, S8, S9, S10).

Table 2. *Study Demographic Information*, Quality Criteria Ratings and Prevalence Rates (ordered by date with most recent first)

Study/ location	Gender	Mean age	Prisoner status	Total sample size	Screening Measure	Clinical int.	Case-note review	Intellect .fuction assess	Adaptive function assess	Onset <18 yrs confirm.	Interviewer/ clinician	Total no. with ID	% with ID	Additional Comments
S1 Murphy *et al.*, (2015) England	M	-	Sentenced	2429	✓	-	-	-	-	-	Disability Liaison Officer / ID Nurse / Education staff	**169**	**7%**	LDSQ used as screening measure then no further assessment completed
S2 Hayes *et al.*, (2007) England	M	33	Sentenced	140	-	-	-	✓	✓	-	Psychologists	**4**	**2.9%**	WAIS-III 7.1% <70) VABS self-rated 10.1% <70 (WAIS-III & VABS 2.9% <70)
S3 Mottram (2007) England	M/F	33	Remand/ Sentenced	260	✓	-	-	✓	✓	-	Psychologists	**17**	**6.7%**	HASI used but not as initial screening measure, WAIS-III & VABS (self-rated)
S4 Robinson (2005) Scotland	M	31	Remand/ Sentenced	88	✓	-	-	✓	-	-	Psychologists	**1**	**1.1%**	Basic functional questions, HASI used as screening measure & WAIS-III
S5 Singleton *et al.*,(1998) England & Wales	M/F	-	Remand/ Sentenced	3141	✓	-	-	-	-	-	Lay interviewers	**268**	**8.5%**	Quick Test IQ <75 (Ammons and Ammons, 1962) used as screening measure
S6 Birmingham *et al.*, (1996) England	M	28	Remand	441	✓	✓	✓	-	-	-	Psychiatrists	**6**	**1.4%**	Quick test used as screening measure & clinical interview designed for study
S7 Maden *et al.* (1996) England & Wales	M/F	-	Remand	820	✓	✓	✓	-	-	-	Psychiatrists	**9**	**1.1%**	Quick test used as screening measure
S8 Murphy *et al.*, (1995) England	M	30	Remand	157	✓	-	-	✓	-	-	Psychologists	**0**	**0%**	Functional questions used as screening, British Ability Scales (BAS; Elliott *et al.,* 1983) & WAIS-R
S9 Maden *et al.*, (1994) England & Wales	F	29	Sentenced	258	-	✓	✓	-	-	-	Psychiatrists	**6**	**2.3%**	Functional questions & Clinical Interview Schedule (CIS; Goldberg *et al.,*1970)
S10 Gunn *et al.*, (1991) England & Wales	M/F	26	Sentenced	2042	-	✓	✓	-	-	-	Psychiatrists	12	**0.6%**	CIS, reading age assessment measure & interviews with prison staff

1.4.3. Methodological Quality Review

Table 3. Study Quality Criteria Ratings below displays the ratings for each of the individual methodological quality criteria rating in order to provide a clear overview of relative methodological strengths. See *Appendix 3*. Prevalence Critical Appraisal Instrument for the full wording of each methodological criterion.

Overall methodological quality of the ten included studies was *moderately low.* In relation to the number of methodological quality criteria met, the studies were found to demonstrate little variation in the range of methodological quality with studies meeting between only 4 of 10 of the quality criteria (S1, S4) to 6 of 10 of the quality criteria (S5, S7, S8, S9, S10). The average number of quality criteria met by each study was 5.3 of 10. There were very distinct trends observed in the specific methodological quality criteria that the studies tended to meet. These patterns of relative methodological strengths and weaknesses are discussed below.

1.4.4 Quality of Sample

All of the studies demonstrated relative methodological strengths in relation to sampling. This was demonstrated specifically in relation to *Criteria 1. Was the sample representative of the target population?* All of the studies included were deemed to have adequately met this criteria. The level of detail provided regarding sampling was good, with the majority of studies (n= 6 of 10) employing randomised sampling methods from three or more UK prisons (S1, S3, S5, S7, S9, S10), and three larger scale studies recruiting randomised samples from sixteen or more UK prisons (S5, S7, S10).

It is noted that these three larger scale studies also included open and closed prisons as well as local and training prisons in their samples, providing a very representative sample across the UK prison estate.

Table 3. *Study Quality Criteria Ratings* (ordered by date with most recent first)

Study	1. Representative sample	2. Appropriate recruitment	3. Adequate sample size	4. Subjects & setting described	5. Sufficient data analysis	6. Std. diagnostic criteria for ID used	7. Reliable measurement of ID	8. Appropriate statistical analysis	9. Confounding factors identified	10. Subgroups identified by obj. criteria	Total no. criteria met by study
S1 Murphy *et al.*, (2015)	✓	✓	✓	-	x	x	x	✓	x	x	4/10
S2 Hayes *et al.*, (2007)	✓	✓	✓	-	✓	x	x	✓	-	-	5/10
S3 Mottram (2007)	✓	-	✓	✓	✓	x	x	✓	x	x	5/10
S4 Robinson (2005)	✓	✓	x	✓	x	x	x	✓	x	x	4/10
S5 Singleton *et al.*, (1998)	✓	✓	✓	✓	✓	x	x	✓	x	x	6/10
S6 Birmingham *et al.,* (1996)	✓	✓	✓	✓	x	x	x	✓	x	x	5/10
S7 Maden *et al.*, (1996)	✓	✓	✓	✓	✓	x	x	✓	x	x	6/10
S8 Murphy *et al.*, (1995)	✓	✓	✓	✓	✓	x	x	✓	x	x	6/10
S9 Maden *et al.*, (1994)	✓	✓	✓	✓	✓	x	x	✓	x	x	6/10
S10 Gunn *et al.*, (1991)	✓	✓	✓	✓	✓	x	x	✓	x	x	6/10

[Key ✓ = Yes, x = No, - = Unclear/ Not Applicable]

The substantial majority of the studies also demonstrated relative methodological strengths in the area of size of sample, specifically in relation to *Criteria 3. Was the sample size adequate?* (n= 9 of 10) of the studies included were deemed to have adequately met this criteria (with the exception of the sample employed in S4). It is noted that only one study (S9) included a sample size calculation within their reported methodology. Therefore adequacy of sample size was calculated using a specific sample size formulation by Naing *et al.,* (2006) as outlined in *Appendix 3*.

1.4.5 Quality of Diagnostic Assessment

All of the studies demonstrated significant methodological weakness in relation to their internal validity via the quality of diagnostic assessment, as rated within *Criteria 6. Were objective, standard criteria used for the measurement of the condition?* None of the ten included studies provided clear evidence of *all three* diagnostic criteria for intellectual disability being met: significant impairment of intellectual functioning, significant impairment of adaptive/ social functioning *and* evidence of onset of these difficulties prior to the age of 18 years (British Psychological Society, 2001; ICD-10: World Health Organisation, 1992).

In relation to assessment of intellectual functioning only a minority of studies (n= 4 of 10) provided evidence of significant impairment of intellectual functioning (S2, S3, S4, S8) using the most widely used measure, the Wechsler Adult Intelligence Scales. Furthermore, a very small minority of the studies (n= 2 of 10) also included a measure of adaptive/social

functioning (S2, S3) using the aforementioned VABS questionnaire. While some of the included studies (n= 6 of 10) referenced employing basic functional questions or more detailed clinical interview (S4, S6, S7, S8, S9, S10), none of these studies clearly reported obtaining information in relation to the age of onset of difficulties. Therefore, in relation to both *Criteria 6.* and *Criteria 7*. none of the ten studies were deemed to have assessed for the presence of intellectual disabilities in an objective and reliable way.

1.4.6 Identification of Confounding Factors and Subgroups

In addition to the above, all of the studies also demonstrated significant methodological weakness in relation to their internal validity via the lack of clarity around identification of confounding factors and subgroup. This was demonstrated within the ratings for *Criteria 9. Are all important confounding factors/ subgroup/ differences identified and accounted for?* None of the ten included studies provided clear evidence of attempts to identify and account for the influence of *all relevant* confounding factors and subgroups, such as prisoners with traumatic/ acquired brain injury, current substance misuse or psychiatric symptomatology, all of which might be expected to adversely affect performance during cognitive assessment. It is noted that some of the larger scale studies (S5, S7, S10) did complete additional assessment for the presence of co-morbid conditions and symptomatology, not all required co-morbidities were accounted for within the data or reporting. Consequently, in relation to both *Criteria 9.* and *Criteria 10*. none of the ten studies were deemed to have adequately attempted to identify and account for the influence of all relevant confounding factors and subgroups.

1.5 DISCUSSION

1.5.1 Summary of Main Findings

The current review investigated the prevalence of prisoners with intellectual disabilities within the UK prison populations. A comprehensive and systematic search led to the review and assessment of methodological quality of ten studies reporting the prevalence of intellectual disabilities in UK prison. The lowest rate of prevalence of prisoners with intellectual disabilities was reported as 0% of the general prison population and the highest rate of prevalence of prisoners with intellectual disabilities was reported as 8.5% of the general prison population. Prevalence of intellectual disabilities in the general UK population has been estimated at 0.3%-0.6% with profound intellectual disabilities and 1–3% with mild-moderate intellectual disabilities (Mental Health Foundation, 2001). In considering the above results in the context of the increase in diversionary routes for offenders with intellectual disabilities, it is reasonable to suggest that intellectual disabilities are over-represented in the prison population.

Distinct patterns were observed in relation to the relative methodological strengths and weaknesses of the prevalence literature to date. Overall the methodological quality rating of *all ten* of the reviewed studies was found to be *moderately low*. There was very little variation in level of quality criteria ratings with all of the studies evaluated only differing between n= 4 of 10 through to n= 6 of 10 in overall quality criteria ratings.

Methodological strengths of the current literature were highlighted in relation to sampling, with ten of the ten included studies employing representative samples and nine of the ten included studies employing samples of adequate size. Significant methodological weaknesses were observed in all (n= 10 of 10) of the included studies in relation to objective and standardised assessment of intellectual disabilities. None of the studies evaluated evidenced *all three* of the standard diagnostic criteria for intellectual disabilities being met (British Psychological Society, 2001; ICD-10: World Health Organisation, 1992). Significant heterogeneity of methods of diagnostic assessment was observed. Half of the studies evaluated relied solely upon basic screening measures, clinical interview and casenote review. Some studies did include some form of direct measurement of intellectual functioning (n= 8 of 10) however there was significant variety in the assessment measure employed and a smaller number of more recent studies did include a direct measurement of adaptive/social functioning (n= 2 of 10). The reliability of the reported prevalence rates was further reduced by *all ten* of the studies failure to adequately identify confounding variables and subgroups within the prison population assessed.

In terms of the development of the literature base, more recent studies were all observed to employ some standardised assessment measure of intellectual functioning and as noted, a small number also employed a direct measurement of adaptive functioning. However the more recent studies overall methodological quality ratings were reduced by failure to report detailed information on study subjects, information regarding the identification of confounding variables and subgroups as well as information in relation to settings.

The current review serves to highlight the sparsity of UK based intellectual disability prison research. The heterogeneity of the assessment measures employed, lack of identification of confounding variables/ subgroups and the moderately low methodological quality of *all ten* of the studies evaluated mean that the reported prevalence rates of prisoners with intellectual disabilities in the UK *must* be interpreted with appropriate caution, within the context of these methodological limitations.

1.5.2 Context of Methodological Limitations

Although all of the ten studies included in the current review shared one of the same objectives of investigating prevalence rates of prisoners with intellectual disabilities in the general prison population, there was significant variance in relation to the type of methodologies utilised. As discussed, none of the assessment measures employed represented an appropriate level of adherence to the standard diagnostic criteria for the diagnosis of intellectual disabilities (British Psychological Society, 2001; ICD-10: World Health Organisation, 1992).

It is reasonable to suggest that the differences in assessment measures employed including their objectivity and reliability may account for some of the variance in the reported prevalence rates. The methodological and classification weaknesses within the literature investigating the prevalence of prisoners with intellectual disabilities is well documented (Loucks, 2007; McBrien, 2003). This review serves to highlight the continuing lack of clarity around the prevalence of prisoners with intellectual disabilities in UK prison populations. As

noted, one of the inherent methodological challenges of the current review, is that *none* of the included studies evidence *all* of the diagnostic criteria being met. This means that comparisons between the presented studies and assumptions of generalisability within the UK can only be made very tentatively, which has significant implications for research, clinical practice, and service planning and development.

1.5.3 Limitations of Current Review

The apparent dearth of UK research, which seeks to evidence all of the diagnostic criteria for intellectual disabilities being met within prison populations, is reflected within the broader inclusion and exclusion criteria of the current review. Arguably one of the limitations of the current review is the lack of rigid adherence to the current diagnostic criteria for intellectual disabilities. As discussed none of the 10 included studies successfully evidenced all three diagnostic criteria met which is an inherent limitation of the literature (Bradley Report, 2009) and accordingly of the current review. In relation to intellectual functioning in particular, it is noted that many of the excluded studies did employ a direct measure of intellectual functioning but failed to report subgroups, presenting IQ scores as <80, or <85.

For the purposes of the current review a clear cut off of IQ (if reported) being less that <75 was employed, as this is representative of the reported criterion employed by many local NHS intellectual disability services (Hayes *et al.,* 2007) however it is noted that this is not in line with current diagnostic criteria and more rigid adherence to this could be adopted. Additional

inclusion criteria could also include constraints in relation to the validity and reliability of any direct intellectual assessment measures employed or in relation to the representativeness of sample of prisoners dependent upon the amount of time served in their custodial sentence (Noble & Conley, 1992). Further inclusion criteria could also be established in relation to the validity and reliability of any direct adaptive functioning assessment measures employed, and their methods of administration.

It could be argued that one of the limitations of the current review is the exclusion of international prison prevalence studies, as per previous systematic reviews (Fazel *et al.,* 2008) as this would allow for the adherence to more restrictive and perhaps reliable inclusion criteria. The current review is limited by the nature of its scope in only assessing UK literature. However, it was hoped that this would improve the generalisability and clinical relevance of any reported prevalence data due to the aforementioned heterogeneity between different countries diagnostic classifications, Criminal Justice Systems and diversionary routes for offenders with intellectual disabilities.

The current review benefited from employing a pre-existing critical appraisal tool which had been piloted with favourable results (Munn *et al.,* 2014). However, one final limitation can be viewed in the need for further formalised and rigorous assessment of this tool in order to facilitate any further improvement of the tool and therefore increase its validity (Harder, 2014).

1.5.4 Research Implications

Primarily the findings from the current review reflect the previous variability in reported rates of prevalence of intellectual disabilities in UK prison populations (Loucks, 2007). It is recognised that there are inherent challenges in attempting to adhere to robust clinical standards in researching large, albeit relatively static, prison populations (Bradley Report, 2009). There are also research implications and challenges in relation to the evolving conceptual and diagnostic constructs of intellectual disabilities. There remains slight definitional and linguistic differences between diagnostic frameworks, mental health legislation, governmental policies and legal frameworks within the Criminal Justice System. The origins of our current definition is rooted in concepts of 'feeble mindedness', 'mental deficiency' and 'developmental arrest' which result in an impairment of social and adaptive functioning (Mental Deficiency Act, 1913 as cited in Holland *et al*., 2002). While these constructs of intellectual impairment, social impairment, adaptive impairment and developmental onset have remained relatively stable, the operationalisation of these constructs into diagnostic criteria has been the subject of much discussion.

The inclusion of a measure of intellectual functioning was first introduced by the American Association of Intellectual and Developmental Disabilities (previously American Association of Mental Retardation (Herber, 1961) with an IQ cut-off of < 85, this was subsequently reduced to an IQ cut-off of < 70 (Grossman, 1973). In terms of the current operationalised diagnostic criterion in relation to intellectual functioning in the UK, as noted previously, this remains as a cut-off of an IQ < 70 (British Psychological Society, 2001; ICD-10: World Health Organisation, 1992). However previous research has disputed the rationale behind the arbitrary IQ cut off (Flynn, 2000) and how this may correlate to measures of adaptive functioning. In addition to

issues with the diagnostic thresholds, Leyin (2006) has also highlighted concerns that the current measures of intellectual functioning do not reliably measure the processes and skills they are intended to, when administered with individuals with an intellectual disability. There are associated implications and indeed challenges for future prison prevalence research in relation to the ever changing and constantly updated psychometric measures and their norms which may increase the number of individuals within the general (and the prison) population that fall within the intellectual disability range on standardised assessments (Flynn, 2000).

In consideration of the continued assessment of intellectual functioning in future research, ICD-10 (World Health Organisation, 1992) identifies sub-classifications of intellectual disability based upon IQ cut offs, and the American Association of Intellectual and Developmental Disabilities (AAMR, 1992) introduced different sub-classifications based upon levels of support required. Talbot (2008) emphasises that individuals with intellectual disabilities represent an extremely heterogeneous clinical population and it may be useful to explore these subgroups in relation to forensic populations. It is also suggested that future research must focus on identifying and differentiating between all individuals on this continuum in order to provide evidence for an accurate representation of the associated support needs, this may not be achieved through assessment of intellectual functioning alone (Talbot, 2008).

It remains important to recognise that conceptually and linguistically, our definitions of intellectual disability do remain grounded within deviations in intellectual functioning/ IQ cut offs and the above diagnostic frameworks all contain references to significant impairments

in intellectual functioning. However, the British Psychological Society (BPS, 2001) emphasises the importance of consideration of the biological, psychological, environmental, social and cultural contexts within an individual assessment, while cautioning against overdependence on measures of intellectual functioning. Most recently the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) by the American Psychiatric Association (2013) also emphasises the importance of adaptive functioning, in conjunction with intellectual impairment. The lack of measures of adaptive functioning within the current study highlights the need for further more robust research in this specific area within forensic populations.

Future prevalence research within the forensic population should continue to assess intellectual functioning but this must be contextualised to prevent over-dependence upon measures of intellectual functioning in research and clinical practice. The potential risks of maintaining sole focus on IQ cut offs have been well documented, particularly when facilitating or negating access to particular intellectual disability services (British Psychological Society, 2001). While measures of intellectual functioning can be useful in predicting academic functioning, there is much less evidence that such measures are reliable in predicting adaptive or social functioning and therefore associated support needs (Sternberg *et al.*, 2001).

Most recently, Webb and Whitaker (2012) again highlighted the need for a more 'clinically meaningful 'operational definition and sub-classifications of intellectual disabilities. This may include conceptualising intellectual disabilities in relation to impairment of adaptive functioning (Flynn, 2000) or in relation to risk and social competence (Greenspan, 1994). This may also include development and further research into the American Association of

Intellectual and Developmental Disabilities (AAMR, 1992) 'systems of supports' which Leyin (2010) suggests has the potential to overcome difficulties associated with assessment and sub-classification of intellectual functioning. While a systems of support framework may be more easily translated into service delivery for the general population, similar to the assessment of adaptive functioning, their remains inherent challenges in applying this to prison populations in research and clinical practice. Future research may consider the prevalence of intellectual disabilities in prison populations based upon a proposed definition of intellectual disability which incorporates all of the above conceptual frameworks (Whitaker, 2008). More considered adherence to diagnostic frameworks will help to ensure reliability and generalisability of forensic intellectual disability prevalence research (McBrien, 2003).

1.5.5 Professional Practice Implications

The findings from the current review serve to highlight significant implications for professional practice. The variance reflected in the prevalence research results in professional practice challenges from an individual level (McArdle, 2010), to a public protection practice level (Lindsay *et al*., 2004), through to a service development level (Badger *et al*., 1999) and even to a legal level in relation to how we might achieve balance between custodial pathways and diversionary pathways (Maden, 2003).

There is consensus that it is optimal to identify offenders with intellectual disabilities as upon first entering the Criminal Justice System, despite this there are identification issues at each stage (Cant, 2007). Myres (2004) reported that there are at least five separate mechanisms that could trigger identification upon entry to prison. The large scale studies presented within the

current review serve to highlight the fact that, in contrast with other stages in the Criminal Justice System, prisoners represent a comparatively static population for whom full assessment can be facilitated (Glaser & Greifinger, 1993).

However, the methodological limitations of the research presented within the current review are representative of the inherent challenges of full assessment which can be time consuming and has significant implications in relation to resources required (Bradley Report, 2009). Currently the information accompanying offenders to prison is unlikely to report the presence of intellectual disabilities (Herrington *et al., 2004;* Talbot, 2008). Therefore the context provided by the current review further highlights the need for pre-assessment screening in order to conserve financial and staff resources.

A recent joint report by HM Inspectorate of Prisons and HM Inspectorate of Probation (2015) highlighted that very few prisons currently utilise routine screening or assessment measures. Previous screening research has highlighted the lack of systematic application of screening measures (Murphy *et al.,* 2000). As discussed there is no current '*gold-standard'* in screening measures for intellectual disabilities (Loucks, 2007). The need for development and use of relatively quick screening measures is recognised across clinical and forensic populations (British Psychological Society, 2003). Routine implementation of screening measures such as the LDSQ (McKenzie & Paxton, 2006) or the HASI (Hayes, 2000) within prison populations is recommended as a priority (HM Inspectorate of Prisons & HM Inspectorate of Probation Report, 2015). However it is important to recognise that the introduction of routinised screening merely represents the first step within professional practice change and there needs

to be an adequate system in place to support the needs of prisoners with intellectual disabilities (McKenzie *et al.,* 2012; Murphy *et al.,* 2015).

As noted, there is a clear consensus for the need for screening and identification of prisoners with intellectual disabilities however there is less clarity around how to best support the needs of prisoners with intellectual disabilities. Additionally, there is evidence of the need for appropriate training skills and rehabilitative treatment programmes to be adapted specifically for the intellectually disabled population (Barron *et al*., 2002; Herrington *et al*., 2005). Beyond the accessibility and inclusiveness of 'mainstream' training and treatment programmes there is also a question around the more general inclusion of prisoners with intellectual disabilities.

When considering the needs of this population in community settings, historically there has been a marked shift from the pre-1970's culture of segregation and institutionalisation (Department of Health, 1971). The process of deinstitutionalisation has led to an increased community presence and community engagement for individuals with intellectual disabilities (O'Brien & Tyne, 1981) and the development of community-based models of support (Scottish Executive, 2000; Scottish Executive, 2013). As discussed previously, parallel integrative processes have occurred within educational settings with the mainstream inclusion movement. This has resulted in many children and young people with intellectual disabilities being supported to attend mainstream educational placements, although 'full inclusion' is often critiqued and rarely attained (Kauffman & Hallahan, 2005).

Historically, mental health services across the UK have provided care within specialist Community Learning Disability Teams (CLDTs) that remain separate from general adult

mental health services in provision of both inpatient and outpatient care. As with education, health and social care services now advocate for the right for individuals with intellectual disabilities to access general health services, with the provision of 'reasonable adjustments' wherever possible (Scottish Executive, 2013). However, the lack of specialist training among 'general' practitioners and has led to requests for additional training to be completed and consultancy provided in order to facilitate the implementation of this integrative model (Royal College of Nursing, 2013).

In relation to professional practice implications, as with health, social care and education settings, within the prison setting issues of integration remain contested. Many UK prisons continue to maintain Segregation Units or Close Supervision Centres (CSCs) where prisoners are housed separately from the main prison population. A recent report by the Prison Reform Trust (2015) highlighted that these units house both the most challenging and the most vulnerable prisoners, including those with intellectual disabilities. Given the reported adverse affect of segregation on prisoner's mental and physical health, the Prison Reform Trust suggested that the function and use of such units must be carefully considered within prisons.

While Talbot (2008) made a number of recommendations regarding how best to support prisoners with intellectual disabilities, the segregation of all prisoners with intellectual disabilities was not included and this would appear to be out of sync with developments in health, social care and education. A historic review of the needs or mentally disordered offenders (including offenders with intellectual disabilities) highlighted the need for diversionary routes, reporting that the needs of this population are best met within

community rehabilitative placements rather than custodial settings (Reed Report, 1992). Within the context of the sparisty of intellectual disability prison research highlighted in the current review, further clarification around the prevalence of prisoners with intellectual disabilities in the UK is required, with identification being a clear prerequisite to any practice considerations of integration or segregation.

1.5.6 Conclusions

The findings of the current review demonstrated rates of prevalence of prisoners with intellectual disabilities within the general UK prison population ranging between 0% - 8.5%. Distinct patterns were observed in relation to the relative methodological strengths and significant weaknesses of the prevalence literature to date. This review documents the historical and continuing lack of clarity around the prevalence of prisoners with intellectual disabilities in UK prison populations, meaning that caution must be exercised when synthesising the results of the current review. The current review also serves to highlight the need for further consideration between the current standard diagnostic criteria for intellectual disabilities and research methodologies. Additionally, the current review serves to highlight the importance of identification of prisoners with intellectual disabilities and implications for professional practice are considered.

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CHAPTER 2. EMPIRICAL PAPER

Transitionary Experiences of Offenders with Intellectual Disabilities: A Qualitative Exploration

Running Title: Transitions and Intellectually Disabled Offenders

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2.1 ABSTRACT

Background

Reforms in legislative practice and developments in models of offending behaviour have resulted in the development of community-based services for offenders with intellectual disability. Provision of good quality transitionary care for this population presents remains challenging and there is an increasing need to develop a more collaborative and person-centred measure of the '*successfulness*' of these transitions.

Methodology

Semi-structured interviews were conducted with seven male offenders with intellectual disabilities regarding their experiences of transitioning from inpatient to community-based services. Interviews were analysed using Interpretative Phenomenological Analysis.

Results

Analysis of the data resulted in the identification of five master themes: Relationships with Staff, Lived Experience of Transition, Steps towards Freedom, Community Embeddedness and Different Concepts of Self.

Conclusions

Suggestions are provided for future research in relation to active participation of individuals with intellectual disabilities. The importance of employing newer models of offending behaviour in professional practice is considered.

Keywords: Forensic, secure services, criminal justice, intellectual disabilities, transition.

2.2 INTRODUCTION

The provision of transitional care for offenders continues to be an area of challenge for health, social and Criminal Justice Services (Bradley Report, 2009). Addressing this challenge is particularly key in meeting the needs of mentally disordered offenders (offenders with psychiatric co-morbidities and/ or intellectual disabilities). Mentally disordered offenders, particularly those with intellectual disabilities, face many co-morbid difficulties including poorer health outcomes, deficits in social and community support (Hayes, 2007; Loveland & Boyle, 2007) and commonly have histories of early deprivation and abuse (Royal College of Psychiatrists Faculty Report, 2014). This group are subsequently disadvantaged at various stages of the Criminal Justice System (Talbot, 2008) and therefore represent an extremely vulnerable forensic population with complex needs (Simpson & Hogg, 2001).

2.2.1 Service Development Recommendations & Developments

A historic review of health and social services for mentally disordered offenders emphasised the need for diversionary routes, reporting that this populations needs are best met within community rehabilitative placements where they can receive appropriate, person-centred health and social care (Reed Report, 1992). The move toward the personalisation of service provision is also paralleled within general intellectual disability service recommendations and good practice guidelines (Department of Health, 2001a, Department of Health 2002; Scottish Executive, 2000a). The potential benefits of person-centred service provisions relate to an overall improvement in quality of life including increased access to social networks, increased

community involvement (Robertson *et al.*, 2005). Additionally, a focus on provision of community-based services and placements was also supported within the Scottish Executive's Report which called for improved provision of community services for mentally disordered offenders who were transitioning from inpatient and secure services (Scottish Executive, 2004).

The Mental Health (Care and Treatment) (Scotland) Act, (2003) led to the introduction of Community Treatment Orders and amendment of Compulsion Orders which have provided the legislative foundations for community based support. Such legislative reforms have ensured further development of local community-based rehabilitative services to support mentally disordered offenders in their journey through the Criminal Justice System. Additionally, the introduction of the healthcare led Care Programme Approach (Department of Health, 2008a) was designed to formalise (person-centred) throughcare and post-discharge planning between agencies and ensure appropriate risk management (Scottish Executive, 2015).

2.2.2. New Models of Offending Behaviour

In addition to the development of community-based services, new rehabilitative models of offending behaviour have emerged. The development of the Risk-Needs-Responsivity Model (Andrews & Bonata, 1998) heralded a move away from more confined 'one size fits all' models

of risk management (Jeglic *et al.,* 2011). This model proposed that offender interventions must be adapted in accordance with fluctuating levels of risk and interventions must address wider unmet needs.

The subsequent strengths-based Good Lives Model (Ward & Brown, 2004) of offending behaviour and rehabilitation was developed via the synthesis of biological, psychological and social research. This model proposes that the purpose of all human behaviour (including offending behaviour) represents an attempt to meet a selection of eleven core needs or '*primary goods'*. Primary goods can be "states of affairs, states of mind, personal characteristics, activities, or experiences that are sought for their own sake and are likely to increase psychological well-being if achieved," (Ward *et al.,* 2007, p.90).

> These include: 1) *life* (including healthy living and optimal physical functioning, sexual satisfaction, 2) *knowledge* (how well informed one feels about things that are important to them), 3) *excellence in play* (hobbies and recreational pursuits), 4) *excellence in work* (including mastery experiences), 5) *excellence in agency* (autonomy and self-directedness), (6) *inner peace* (freedom from emotional turmoil and stress), 7) *relatedness* (including intimate, romantic, and familial relationships), 8) *community* (connection to wider social groups) 9) *spirituality* (in the broad sense of finding meaning and purpose in life), 10) *pleasure* (feeling good in the here and now) and 11) *creativity* (expressing oneself through alternative forms).
>
> (Ward *et al.,* 2007, p.90).

This strength based model proposes that offences represent attempts to meet these unmet needs and therefore rehabilitative programmes must attempt to address these deficits of unmet needs in order to reduce risk of recidivism. In considering this model in the context of the increase in community rehabilitate approaches it is apparent how such placements would better meet the needs of offenders. However, despite the progress in the development of community services for mentally disordered offenders, supporting legislative frameworks and models of offending behaviour, there continues to be difficulties in ensuring continuity and quality of care (Bradley Report, 2009).

2.2.3 Associated Challenges of Transitions

Mentally disordered offenders typically transition through reducing levels of security before reaching community-based services that provide increasingly 'community-facing' rehabilitative interventions (Forensic Mental Health Matrix, 2011). However such transitions do not always occur a linear fashion and the transitionary processes can occur in many different ways (Myres, 2004). Recent pathways research demonstrated that mentally disordered offenders' journeys through health and social care services are markedly diverse (Lindsay *et al.*, 2010). This is likely to be representative of the heterogeneity and complexity of this population and the number of different agencies and sometimes different localities involved in these transitions.

The importance of multi-agency working is well established within the literature (Myers, 2004) and is reflected within the legislative frameworks such as the Care Programme

Approach (Department of Health, 1990). However the involvement of a number of different agencies also represents inherent challenge in transitions and discharge planning. For example, challenges in interagency information sharing are recognised (Hayes, 2007), effective interagency communication is required to facilitate transition planning, structured risk assessment and risk management (National Association for the Care and Resettlement of Offenders, 2007).

Additionally, transitions can be further hindered, and at times significantly delayed, by shortages or '*gaps*' in community resources and placements (Myers, 2004; Mansell, 2010). This has included lack of appropriate supported residential placements and inpatient beds at lower level secure units. Retrospective review has demonstrated that forensic inpatients' lengths of admissions in secure settings are up to ten times longer than generic psychiatric inpatients (Raina & Lunsky, 2010). This is in direct contravention of the Millan Principles outlined in the Mental Health (Care and Treatment) (Scotland) Act, (2003) which emphasise the need for least restrictive approaches when delivering care. This also has significant implications for the delivery of inpatient services and availability of hospital beds in terms of patient through-put. Again, this pattern is likely to be representative of the complexity of this population who require a significant amount of support to transition to community services (Royal College of Psychiatrists Faculty Report, 2013).

2.2.4 Evaluating Outcomes

There is consensus that the consequences of '*poor*' transitions are significant at an individual level and that of public protection. Following transitions from secure and custodial settings, offenders with mental health problems often face challenges in securing appropriate accommodation and employment and lack appropriate support from local mental health services (Keil *et al.,* 2008). This can in turn lead to increased risk of suicide, re-admission to hospital and increased rates of recidivism (Draine & Solomon, 1994; Keil *et al.*, 2008).

Debate continues over how professionals measure and define the '*successfulness*' of transitions. Historically, the success of transitions and efficacy of any offender rehabilitative behaviour programmes have been measured by rates of recidivism (MacCulloch & Bailey, 1991), psychiatric symptomology, or rates of readmission to hospital (Royal College of Psychiatrists Faculty Report, 2013). In response to the principles of the Risk-Need- Responsivity Model (Andrews & Bonata, 1998), research has also focused upon specific confines that relate to offender risk as a means of evaluating rehabilitative outcomes rather than priorities which individuals may set for themselves in relation to rehabilitation (McMurran & Ward, 2004). Whilst adherence to the guiding principles of the current legislation can be (and should be) readily evidenced by services, this alone does not provide direct data in relation to service user satisfaction or quality of life (Fish & Lobley, 2001). While this type of quantitative data is relatively easy to sample, over-reliance upon rates of recidivism is arguably too simplistic, placing greater significance on offending behaviour than offenders needs (Blackburn, 2004).

These types of methodology appear to be conflict with the recent development of person-centred, needs based models of offending, in not exploring wider, systemic issues as well as the individual needs and priorities of the offender (Good Lives Model; Ward & Brown, 2004). Such models of offending behaviour have redefined 'treatment' and broadened the scope of interventions from risk reduction to increasing positive and protective factors. This combined with an increasing recognition of the complexity of factors which affect efficacy of treatment and influence post-discharge outcomes (Fitzgerald, 2011), demonstrates that success of transition cannot be accurately conceptualised or measured in such a rudimentary way (Friendship *et al.,* 2010).

The Department of Health (2008b) suggested that outcomes must be rigorously measured across three separate domains: i) effectiveness of treatment, ii) patient (and public) safety and iii) *patient experience*. This is also supported by developments in professional practice which emphasise the drive to support service users to become active partners in the development of the services which support them (Scottish Executive, 2000b; Scottish Executive 2001). Inclusion and collaboration are also identified as key cornerstones in the disability rights movement (Charlton, 1998). Thus there is a role for both quantitative and qualitative data in research with this marginalised population.

2.2.5 Service User Involvement in Research

In order to further explore the transitionary experiences of offenders with intellectual disabilities there is a need to actively engage this population in *their own* research.

Historically, the traditional paradigms of psychosocial research have resulted in a lack of active engagement of individuals with intellectual disabilities (Emerson, 1985; Lindsay *et al.*, 2012). It is suggested that the lack of participatory research methodologies has '*alienated*' this population by failing to provide individuals with intellectual disabilities with an opportunity to share their experiences (Oliver, 1992, p.105). This has also resulted in significant '*gaps*' in our understanding of the experiences of offenders with intellectual disabilities (Hollomotz, 2014). The growing need to actively include individuals with intellectual disabilities in the research process is well evidenced within the literature (Bradley Report, 2009; Myers, 2004, Walmsley & Johnson, 2003).

A recent large scale review highlighted some progress in adapting narrative and qualitative methodologies to actively involve offenders with intellectual disabilities in the research process (Hollomotz, 2014). This has included exploring experiences of admission and treatment within generic and specialist mental health services (Longo & Scior, 2004) and service user satisfaction in a secure forensic intellectual disability unit which demonstrated that service users can provide invaluable accounts of their own experiences (Woods *et al.*, 2008) and unique views on different models of offending behaviour (Barnao *et al.*, 2015).

In addition to this richness of data, it has also been argued that there is a moral and ethical need to actively involve individuals with intellectual disabilities in the research process (Goodwin *et al.*, 1999). Qualitative methodologies can provide a unique opportunity for marginalised and excluded populations to be have their say, and to be heard via conventional

academic discourse (Booth, 1996). Thus there continues to be a need to move beyond the margins of psychometric and quantitative methodologies, in order to allow individuals with intellectual disabilities to share their experiences and define them in their own terms (Hollomotz, 2014).

2.2.6 Rationale – Empirical Study Aims

Following the recent development of community based services and community based treatment orders, methodologies for measuring the success of transitions has focused upon risk, recidivism and readmission. Concurrent developments in research and legislative practice demonstrate an increasing need to actively engage individuals with intellectual disabilities in the research process by exploring the lived experiences of this population. Within this context the current study aims to address the gap in the current literature by exploring the transitionary experiences of offenders with intellectual disabilities, utilising a qualitative approach. It is hoped that this will offer valuable insight into offenders' experiences while providing an alienated population with an opportunity to share their experiences and reflections.

2.3 METHODOLOGY

2.3.1 Interpretative Phenomenological Analysis (IPA)

Within the context of the existing gaps within the outcomes based literature it was deemed that a qualitative approach would best provide a rich and detailed account of individuals' experiences (Patton, 2002). An Interpretative Phenomenological Analysis (IPA) methodology was employed (Smith *et al.,* 2009) as it has been demonstrated to be useful in capturing *processes* rather than attempting to classify *outcomes* (Willig, 2001), and has been well established with this population. IPA seeks to explore how individuals experience their world and what meaning is attributed to experiences. The epistemological stance of IPA reasons that an understanding of others experiences can only be accessed via the researcher's engagement and interpretation of each individual's subjective account (Smith *et al.,* 2009).

2.3.2 Ethical Considerations

Issues of consent are central to any research involving the participation of individuals with intellectual disabilities (Nind, 2008) and is a fundamental principle of all ethical research (Department of Health, 2005). In order for an individual's consent to be valid they must i) be capable of making that particular choice, ii) acting on a voluntary basis and iii) be provided with adequate information to enable them to make an informed choice (Department of Health, 2001b). Issues in relation to vulnerable populations and capacity to consent in clearly outlined within the Adults with Incapacity (Scotland) Act (Scottish Executive, 2000c). Regarding participation in research, informed consent is defined as the voluntary participation following

the provision of accessible information which outlines what participation involves and the associated harms and potential benefits (Royal College of Nursing, 2011). In order to ensure informed consent was provided by participants a number of steps were taken.

In relation to procedures, a stepped recruitment procedure was applied and initial contact was not made via the researcher in order to avoid conflict of interest and attempt to address imbalances of power in decision making (Harris, 2003). In accordance with conceptualising consent as an ongoing process (Department of Health, 2001b; Royal College of Nursing, 2011) consent was revisited at several occasion during the research process. The need to revisit consent is particularly important with qualitative methodologies such as IPA where the exact direction and content of data collection cannot be predicted or guaranteed (Houghton et al., 2010). In order to assist in this, active engagement of community care staff in the research and recruitment process ensured that participants could be reminded of procedures and consent at any point, facilitating understanding of the research process (Warren, 2002). A minimum amount of time (48hours) between opt-in, consent and participation was ensured in order to prevent pressure and address issues of acquiescence (Goldsmith *et al.*, 2008).

Provision of intervals in the recruitment process ensured that participants could be supported to access the participant materials over time (Brooks & Davies, 2008). In relation to participant materials, accessibility of information can have a direct impact on an individual's capacity to consent (Nind, 2008). In order to ensure accessibility of written information, the design and

content of all participant materials were created in direct consultation with a Speech and Language Therapist and were informed by current best practice guidelines (Department of Health, 2010). Additionally, all participant materials were reviewed by a local 'Accessible Information' focus group (consisting of service users with intellectual disabilities) and were adapted accordingly.

2.3.3 Ethical Approval

Initial review and ethical approval was granted by the DClinPsychol Ethics Committee within the University of Edinburgh. Following local Caldicott Guardian Approval, local ethical approval was granted by the NHS Research and Development Department (see *Appendix 4.)* and NHS Medical Research Ethics Committee (see *Appendix 5.)*

2.3.4 Sampling

IPA recommends that a smaller, more homogeneous sample should be recruited in order to facilitate more in-depth analysis from individual participant's accounts (Larkin *et al.*, 2006). This smaller size of sample should also enable the exploration of these issues across the sample as whole (Smith *et al.*, 2009). In keeping with the methodological principles of IPA, purposeful sampling was employed in order to achieve as homogeneous a sample as was practicable within the confines of the current study. This meant that for the purposes of the current study, as per the principles of purposeful sampling, forensic service users were specifically recruited

to participate in the research interviews. Recruitment of this specific sample was based upon their lived experience and thus assumed 'expertise' in the transition phenomenon explored. Therefore a process of purposeful sampling was employed as opposed to attempting to recruit a randomised sample or a sample, which may be representative of the wider forensic population (Patton, 2002; Suri, 2011).

2.3.5 Inclusion and Exclusion Criteria

Table 1 outlines the inclusion criteria employed. Within the staged process of recruitment eligibility was initially assessed by local forensic community service providers and then confirmed via consultation with NHS specialist Forensic Learning Disabilities Service (FLDS) staff. This included the Registered Medical Officer (RMO) and Consultant Clinical Psychologist.

Table 1. *Study Inclusion and Exclusion Criteria*

Participant Inclusion Criteria
1. Adults >18 years (both male and female). 2. Mild – high moderate diagnosis of intellectual disability. 3. English speakers with adequate verbal communication abilities. 4. Charged or convicted of a criminal offence and have been through the Criminal Justice System, (Including all types of offences and including all levels of court proceedings). 5. Currently receiving input from the specialist Forensic Learning Disabilities Service (FLDS). 6. Transitioned from inpatient secure forensic services to community-based forensic services. 7. Able to provide informed consent to participate in the research.
Participant Exclusion Criteria
1. Currently experiencing severe mental health problems e.g. acutely psychotic. 2. Currently using alcohol or substances.

Age restrictions were employed to recruit an adult population. The lower age limit was set at 18 years old and no upper age limit was set in representation of the threshold utilised by the majority of learning disability services within the UK. All participants had been through the Criminal Justice System in order to recruit as homogeneous a sample as possible. Within the current service, as with the majority of FLDS this is also requirement to receive service input. Further homogeneity was achieved through ensuring all participants had transitioned from inpatient secure forensic services to community-based forensic services. Time since transition was guided by the characteristics of the target research population and an identified cut-off time since the transition was not included in the current study.

Participants were only included who fell within the mild – higher end of moderate intellectual disability (IQ 40-70) based upon diagnostic criteria in ICD-10 (World Health Organisation, 1992). Confirmation of this was obtained via consultation with FLDS staff who had a good working knowledge of the participant's level of functioning and who had access to current and historical information including standardised measures of intellectual functioning. This served to ensure the recruitment of as homogenous a sample as was practicable. This also ensured that the participants identified by staff were the most likely to have the capacity to consent and the adequate verbal communication abilities to understand and meaningfully engage in the research process.

Capacity to consent was ensured by confirming that participants had the ability to a) act on decisions, b) make decisions, c) communicate decisions, d) understand decisions and e) retain

memory of the decisions (Scottish Executive, 2002c). This was initially judged by community staff and then confirmed by specialist FLDS staff and by the principal researcher during pre-interview participant meetings. Related to issues of consent 'adequate verbal communication' abilities was used to cover adequate levels of both expressive and receptive language. Again, this was initially assessed by community staff and then confirmed via consultation with FLDS staff.

Current input from the specialist FLDS was necessary to ensure the safety of both participants and researcher. Consultation with specialist FLDS staff was required to confirm adherence to the above inclusion criteria and to provide specialist guidance on issues of capacity to consent and risk management. Current input included, but was not limited to: psychological assessment and intervention, completion of rehabilitative programmes and risk assessment and management.

2.3.6 Recruitment

Recruitment was conducted via a staged process (as outlined within Appendix 6.) in order to facilitate the purposeful sampling of participants and accommodate the aforementioned ethical considerations. Initial contact was made with local forensic community service provider managers and information in relation to the study was discussed *(See Appendix 6. Staff Information Sheet).* Distress and safety protocols were formalised via consultation with NHS forensic staff at this stage *(See Appendix 7. Safety Protocol & Appendix. 8 Distress Protocol).*

Staff were then asked to identify potential participants who would meet the inclusion criteria outlined previously in Table 1.

Initial contact with the potential participants was made by community service key workers who knew the participants well. Participants were provided information in relation to the study (*See Appendix 9. Participant Information Leaflet*) and were invited to complete an opt-in sheet to meet with the researcher to discuss participation, issues of confidentiality and to sign consent forms. This meeting included the involvement of key-workers and assisted in establishing a rapport with participants, which is identified as a fundamental part of completing research with individuals with intellectual disabilities. Following completion of the consent form (*See Appendix 10. Participant Consent Form*) interview dates were arranged in the participant's home environment, where possible.

2.3.7 Participants

Initial consultation with four local community-based offender management services resulted in the identification of nine potential participants who met inclusion criteria. Two individuals declined to participate in the study. An overview of participant characteristics is outlined in Figure 1. below. In order to ensure as high degree of anonymity as possible, individual participant characteristics are not presented.

***Figure 1**. Overview of Participant Characteristics*

Gender : All male
Age: 20-51 years (average age 33 years)
Level of Intellectual Disability: mild - high moderate
Current Community Forensic Service: supported living accommodation, own tenancy
Previous Secure Setting: secure hospital setting, secure school setting
Time Since Transition: 2 years – 11years
Range of Nature Index Offences: sexual offending (or sexually inappropriate behaviour), use of offensive weapon, fire raising and breach of the peace.

2.3.8 Data Collection

Following the completion of risk assessment consultation with the clinical supervisor of this project, interviews were conducted with all seven participants. Interviews employed a semi-structured interview schedule *(See Appendix 11. Semi Structured Interview Schedule.)* This draft attempted to achieve focus, allowing for specific questions to be asked while remaining flexible and open-ended and included a number of initial questions and prompt questions (Willig, 2001; DiCicco-Bloom & Crabtree, 2006).

Five of the seven interviews were conducted in participants' homes, with the remaining two being conducted at community-based services (at the participants' request). Interview ranged

in length from 25 minutes to 70 minutes. Interviews were recorded using a digital recording device. As it was recognised that this method of data collection may have negative connotations for forensic populations (Warren, 2002) a number of steps were take comfort and confidentiality in recording (King & Horrocks, 2010). This included ensuring transparency around recording, actively engaging participants in the recording process, in addition to ensuring strict confidentiality in the data management process and anonymity at the point of transcription.

2.3.9 Data Coding & Analysis

All interview recordings were transcribed verbatim, in accordance with King & Horrocks (2010) interview transcription guidelines. The Nvivo10 (QSR International, 2012) software package was employed for coding and data management. In order to facilitate a reflective engagement with the participants' accounts, data coding and analysis was completed following the core principles of IPA (Smith *et al.,* 2009). The processes of moving from the individual account to the shared account is outlined below:

Step 1: Reading and rereading – to facilitate immersion in the original data by the repeated reading of individual participants' accounts.

Step 2: Initial noting – facilitating a growing familiarity with transcripts through making initial notes on content (descriptive and conceptual) and language used.

Step 3: Developing emergent themes - exploring patterns within the initial notes to capture initial themes.

Step 4: Searching for connections across emergent themes – exploring connections within identified themes, leading to the development of broader (or higher-level) 'super-ordinate' themes.

Step 5. Moving to the next case – repeating steps 1-4 with each transcript, facilitating further identification of existing themes in conjunction with allowing for the emergence of new themes.

Step 6. Looking for patterns across cases – comparison of super-ordinate themes across transcripts with comparisons of recurrent and isolated themes. Integration of themes to develop master themes representing the entire group.

2.4 RESULTS

A total of five master themes: *relationships with staff, lived experiences of transition, steps towards freedom, community embeddedness and different concepts of self.* Within these a further sixteen superordinate themes were identified and incorporated, *See Table 2. Overview of Master and Superordinate Themes.* Distribution of themes varied by participant, *See Appendix 12. Distribution of Themes across Participants.*

***Table 1**. Overview of Master and Superordinate Themes*

Master Themes	**Superordinate Themes**
1. Relationships with staff	Containing: staff as supporters Restraining: staff as supervisors Issues of trust
2. Lived experience of transition	Emotional responses to change Powerlessness: lack of inclusion, choice and information Importance of steps between Adapting to the new Missing the old
3. Steps towards freedom	Increased control and autonomy Increased privacy Remaining restrictions
4. Community embeddedness	Work and meaningful activity Relationships with others Establishing a home
5. Different Concepts of self	Self as forensic service user Forging new identities

2.4.1 Master Theme 1: Relationships with Staff

The first master theme encapsulates participants' varied views and experiences of the significant relationships with staff across health, social care and the Criminal Justice System. There appeared to be three salient issues that participants reflected on in their accounts. This included their relationships with staff which were experienced as supportive and containing and the relationships with staff which were experienced as supervisory, punitive or restrictive and issues of mutual trust in relationships with staff. These three super-ordinate themes are described below.

Containing: Staff as Supporters

Participants' interpersonal relationships with staff were very prominent throughout their accounts. Participants described turning to staff for emotional containment and support at challenging times and described staff as being helpful in activities of daily living.

Additionally, participants perceived both inpatient and community staff as caring, interested in their needs and sharing similar goals for their rehabilitation.

> *Cause the staff want to do things good for you and not to be bad to you. It's good when staff put you in the right direction… What I meaning the right direction, they… they dinnae want you to go back into the hospital… they want you to bide out if the hospital… erm… they write their reports and everything… (P004)*

Restraining: Staff as Supervisors

In addition to the positive relationships and attachments with staff, participants also described conflicting or ambivalent nuances in their relationships with staff. Participants also described experiencing their interpersonal relationships with staff as punitive, restrictive and restraining.

> *I refused medication and that all the time. I was like 'I'm not getting noooo medication. You ain't putting medication down my throat!' … 'Well we'll just put like a needle in your backside!' I was like 'Really?!?' (P005)*

This was met with frustration and participants' language was indicative of conceptualising staff as uncaring bosses, adversaries or enemies.

> *See the staff that work in there… they don't care. All they care about is going in there, doing their shift and then getting paid and going hame again…(P004)*

Participants described anger in relation to the imbalance of power between staff member and service user. This was particularly apparent when participants were describing the planning around their transitions and a sense that staff were omnipotent, holding the keys to freedom.

> *You cannae break the rules because if you break the rules, it'll go against yourself, you've got to bide by everything staff say… to make this work you've got to dae that. 'Cause I learned that a long*

time ago you cannae break the rules or anything in a new place, if you want to bide where you are – you gotta bide by the rules. (P003)

Such experiences of staff appeared to result in participants attempting to deceive staff or attempt to gain control over staff.

Play against the staff means we're gonna hide stuffs in people's bags, DVD's ehmm… things we shouldnae have… but we have them! It doesn't matter where you are… institutions or whatever… you always do the same! (P004)

Issues of Trust

Participants' interpersonal relationships with staff members appeared to be closely linked to issues of mutual trust. When describing pre-transition experiences participants would often reflect upon previous restrictive measures.

Well at one point I got watched like 24 hours a day 7 days a week support from all the staff… And I had to be home by 11pm at night… I wasn't allowed to have children in the house… (P006)

The sense of increased freedom and autonomy post-transition appeared to be closely linked to the sense that decreases in restrictions were representative of an increased level of trust being placed in them by others. This increase in trust appeared to be linked to the self-identity of the offender, the self that is trusted by others. The experience of feeling trusted by staff

appeared to be similarly salient between accounts but was met with very different emotional responses. For some participants this sense of trust was representative of progress and appeared to be viewed positively.

Well, they can trust me to do a lot of things now… But when you're in… like you came out with two members of staff… Well I used to work, I used to work with two members of staff… but now that I'm only working with one member of staff… And that means that they can trust me… for the last, for the last two years!

Some participants were unsure how to adapt to this newfound sense of trust and described emotional responses of suspicion and confusion.

The shock when I first moved to [community location] from [inpatient location] ken I thought there was cameras all hidden because I didnae know… if… this was a… a test? Or something? Or am I still being watched with being in hospital for a long time? (P004)

Confusing can be about, well confusion of how well they place is gonna be ken about staff standards in the places or what level of open they are. I mean you could… well like I got confused the first time, when I was like told by [previous community care provider manager] it was like 'you can go up in front as long as your staff sees you.' (P002)

2.4.2 Master Theme 2: Lived Experience of Transition

The second master theme encapsulates participants' lived experiences of transition – in the moment. Five superordinate themes were incorporated by this reflecting the significance attributed to their experiences of transition. Superordinate themes represented complexity of transitions and participant's ambivalence and mixed responses to this. Super-ordinate themes included emotional responses to change, powerlessness, importance of steps between, adapting to the new and missing the old. These are described below in greater detail.

Emotional Responses to Change

Participants provided accounts of a wide range of emotional responses to their transitions. Accounts were often suggestive of excitement at moving on and looking forward to future freedoms mixed with anxiety surrounding the next steps.

> *I was happy then… because… it was… for me it was, it was moving and then I was thinking it was going to be a bit hard first. (P001)*

Participants described a range of different strategies in coping with their emotional responses to change including reliance on the significant relationships that were also described in their accounts.

And I was, well I was… I was really scared. And I turned round and says, well the way I was going, well the way I was. I was like that, I was really feeling scared and I was saying to myself 'I just dunno'. So I says to my Mum 'I need a cuddle'. (P007)

Powerlessness: Lack of Inclusion, Choice and Information

Lack of inclusion in choices and planning around transitions emerged as a common experience in participants' accounts. This appeared to be linked to issues of trust and the sense of staff having control over participants.

Well when I lived in [previous inpatient location] there was erm… meetings going on but I didn't know nothing about! They were secret meetings, well I called them secret meetings… Erm they was going on for about… 6 months or so (P004)

Well he actually like says to me, 'Well, what do you actually think of the place?' And I says 'Well, it's alright but I think that we probably need to do a bit more… look around!' And he says 'Well, you gotta make your choice up, if you dinnae – I'll make it for you.' (P002)

Well from that it was five years from when I was in hospital, but it was actually delayed to the 20th, but somebody said 'You've gotta wait… patiently… we will get the phone call… from, from [community care provider]'.(P007)

This was accompanied by a desire to be for actively involved in transitioning planning, have greater access to information and be afforded more opportunities for choice.

Well, pretty much if they actually like gave… ken… had an information pack on the place. [3 second pause] And if they say like, 'Ken this is just a wee folder saying like this is [previous community care provider], this is what we do, this is how we help you, support you, such and such…' (P003)

Well, that staff can do is, they can actually have a, they can actually like have a meeting, have a record… or just like have a meeting to like help peoples get to be out, like when people come out of hospital… when they're coming into the community. (P007)

Importance of steps between

Linked to a desire for greater inclusion in planning and decision making was a recognition of the need for steps in between. Participants discussed these steps in relation to processes such as information sharing.

Getting the information? Well tell them about what the service is gonna be about… or whatever they're going to do… Tell them… Like let them meet the staff… Obviously meet the guys, you know tell them what the service is all about… you know… you know show them. (P005)

These steps were also described in relation to participant's accounts of wanting a greater frequency of pre-transition visits or steps between inpatient to outpatient life.

It would be a way of actually getting the person to… see how far ken… independent can go. Like it shows them how to… see how clean you can do the house, how the maintenance would be. (P002)

Adapting to the New

Participants shared similar accounts in relation to the stages of getting to know staff, adapting to their new environments and the challenges in adopting new routines.

You get to know the persons, you get to know what the service is like, you get to know the person's that you'll probably bide 'wi, you get to know pretty much what they're willing to offer. (P002)

Missing the Old

In addition to the challenges in adapting to community living, many of the participants described missing parts of inpatient life. This included missing friends, missing staff members, missing the routine and missing a sense of containment provided.

Well put it this way: in [inpatient facility] I got fed, I got money for fags, I got supplies when I needed them, I got my computer, I had a roof over my head, I was getting three square meals a day. I was getting more support staff and they were alright with me, they helped me. (P006)

Some participants even expressed a desire to return to inpatient services in the context of frustration around remaining restrictions.

Cause they gave me everything I needed to do for coming out here and I just blew it. For coming out and back to the community. To be honest, I wish I coulda been there all my life. (P003)

2.4.3 Master Theme 3: Steps Towards Freedom

The third master theme encapsulates a sense of participants' tentative steps towards *freedom* following their transition to the community. Three superordinate themes were incorporated into this reflecting their experiences of increased control and autonomy, increased privacy which appeared to conflict with the reality of remaining restrictions. These themes are described below in greater detail.

Increased Control and Autonomy

Following their transition to community services, participants offered rich accounts of their experiences of increased control and autonomy. This would often related to activities and places that they could visit, which had been restricted previously.

Everything is within reason in my control, what I get to do, I got that back as well. (P001)

Down by the river… so, yeah, I used to go down there with staff but sometimes now when I'm on my own I go down there – I just go down for the peace and quietness. (P003)

Well freedom it means that I can do my own things. Like I can go to work myself. Like I can go to shopping myself. I can go to clubs myself. And I can go and say to a member of staff 'I need my money for tomorrow!' (P007)

For others, the sense of increased autonomy was apparent in relation to daily living skills and increased independence at home.

But the thing good about now is I can go into the fridge anytime, make myself a coffee! Or a sandwich! Or any of my meals! It's totally different fae being in hospital. (P004)

For others, the sense of increased autonomy was challenging resulting in lack of routine and structure. This inversely led to a sense of things being out of their control quickly and may be linked to themes of missing the old environments and routines.

And… erm… then when I left [inpatient facility] to go to [community setting] the routine just went woooosshh [gesture] downhill! I was in my bed till about half two in the afternoon…(P003)

Well, I went back into that bad spiral… I was back on alcohol… I was back on the drink, I was back on the hash… I met my old friends again and… well you could call them my gang. (P006)

Increased Privacy

Following their transition to community services, participants also talked about their experiences of increased privacy. This was reflected upon in a wide variety of contexts including use of social media, telephone contact with family members or even the experience of being in control of their own environment.

This is my area… and if anybody comes in and oot, there's a doorbell, they can phone ahead or ring the door bell and I'll open the door…(P002)

Remaining Restrictions

In the context of the sense of increased autonomy and control there was frustration in relation to the reality of remaining restrictions in place. Sometimes this appeared to be in relation to offender identity and the desire for restrictions to be lifted can be seen in relation to offender identity as described later.

Well because erm [4 second pause]… being in town with staff all the time… It makes you uncomfortable ken? 'Cause there's a lot of people in town, and I didnae want them to know about staff and things like that. (P004)

2.4.4 Master Theme 4: Community Embeddedness

The fourth master theme encapsulates participants' sense of *embeddedness* or *belonging* within the wider community following their transition from secure services. Three different superordinate themes were incorporated into this in relation to the importance of work and meaningful activity in the community, the importance of, and increased opportunity to develop relationships with others and finally a fundamental sense of establishing a home for themselves in the community. These themes are described below in greater detail.

Work and Meaningful Activity

As part of the rehabilitative process in the community, participants frequently shared their experiences on paid employment, voluntary employment and other forms of meaningful activity.

P: Yeah! I'm gonna be working at [supermarket]. Starting later today! [4 second pause]

I: And how are you feeling about that?

P: Happy! Get out the house… earn some money…(P006)

It's just good to go to work yourself… 'Cause it means like, you can do… you can do whatever you want. You can go on the phone…speak to your mates and all that. (P005)

The importance of work appeared to be related to both financial autonomy and the development of new identities such as self as expert, or self as being in a position of increased power by assisting and mentoring others. This was also recognised as a way of demonstrating progress to staff and in turn receiving positive feedback from others.

And then you'd be pretty much showing them the bottom line, this is an advantage… this is probably an easier goal to go to, like…well like at [work placement] there is… eh… a couple of new people there, well new trainees there… and maybe they don't have a clue how to work tools, drills, garden equipment or anything, and I pretty much like took one of them underneath my wing. (P002)

Relationships with Others

Following their transition to community services, participants offered various accounts of the importance of their interpersonal relationships with others in the community. Participants talked about community life affording increased opportunities of contact with family, friends and significant others.

They do these discos as well so some of the people there, some of them went to other disco and they knows a few new people there, so sat with them. I wonder and I asked one or two of the names to get to know them. (P001)

I missed something out! It's about my family. When I was to meet my family, I was allowed to have eh… them in my flat at [current community placement] for a while but every time I had to meet my family, it had to be arranged meetings with family. (P004)

Where participants were offered choices in relation to the location of community care they received, contact with family was found to be influential in decision making.

Establishing a 'Home'

The theme of establishing a home or roots within community settings was discussed by participants. Participants talked about the ways in which their community settings become more of home to them. This could be in very practical ways, such as receiving support and encouragement from staff to decorate, make improvements and generally get settled.

Well I was happy about getting the kitchen done up, and it's something... And I started taking it on myself, to just patch ah the holes, fill in which bits I can, try to get it to just be a bit more fresh. P002

One participant described the significance of the change from a community forensic service to a home in linguistic terms.

P: So… it was… after my three years I kept getting better and better and I thought, well I'm nae going anywhere else! This is my home!

I: Yeah? And what helped to make it a home for you?

P: To become a home? Ehm… eh… when I used to eh go out with staff I used to call my flat a 'ward'… I called my flat a 'ward' and once you're there all the time then every time I was out or whatever I would says to the staff 'I'm going home'. (P004)

2.4.5 Master Theme 5: Different Concepts of Self

The fifth and final master theme encapsulates participants' reflections on their different concepts of self. Similar to relationships with staff there was a sense of duality in participants' sense of self. This was represented in the contrast between participants' historical sense of self identity, self as 'offender' or self as forensic 'service users' versus the new and the emerging sense of self that participants were given the opportunity to develop following their transition. These themes are described below in greater detail.

Self as Forensic Service User or Offender

Identification of self as a forensic service user or offender often appeared to be presented within the context of punitive relationships with staff or remaining restrictions in the community. Participants spontaneously reflected upon their offending histories.

When I was younger I thought, well ken this if I just stick it out well I can get a copper, be a copper and really change people's life... and then pretty much went down the criminal list instead... (P002)

Accounts such as this were consistently worded in the past tense, perhaps indicating a desire to compartmentalise such parts of their identity. Not all participant accounts conveyed such clear compartmentalisations. For some reflection on this part of their identities elicited responses of shame and a fear of others knowing.

Yeah, some of them kenned my past and that's what I was a bit wary about and everything… I felt… well this is going… when I was at [community location] I felt, one of them, he went onto social… he went onto Facebook and he told everything that I'd done. (P004)

Other participants described fears in relation to re-offending or 'making mistakes' that would result in an increase in restrictive measures or ultimately a return to secure services.

If I make a mistake, it's my fault for making a mistake, not nobody elses, if I end of back in hospital' or stuff like that…(P004)

Forging New Identities

In contrast to the above, participants often described more positive parts of their self-identities emerging post-transition.

'Cause I wanna earn money… my way… not the government way. [3 second pause]…. so I can know I've got a roof over my head… so I can pay my bills… and have a good outgoing… a good standard of life… (P006)

Accounts such as this were consistently worded in the future tense, and encompassed a range of different, or rather more positive projections of self-identity. Such descriptions tended to be linked the experience of being trusted by staff, and valued at work placements. In describing their community placements, participants appeared to be afforded the opportunity to explore different parts of their own identity including the creative self and the autonomous self.

Yeah, and I erm… let it go because I didn't want to dae it anymore… But I'm hoping to get back in contact with them to see if they want to start up…(P004)

2.5 DISCUSSION

2.5.1 Summary of Main Findings

The current study explored the transitionary experiences of offenders with intellectual disabilities, from inpatient secure serviced to community based services. Purposeful sampling was employed in order to achieve as homogeneous a sample as was practicable. A staged process of recruitment resulted in the inclusion of seven male service users in the current study. Confirmation of eligibility for inclusion was confirmed through consultation with NHS FLDS staff. All participants were identified as functioning within the mild-high

moderate range of intellectual disabilities. All participants had experience with the Criminal Justice System and had transitioned between inpatient secure settings to community based services. Participants ranged in age between 20-51 years, the time since transition varied between 2-11 years.

An Interpretative Phenomenological Analysis (IPA) methodology was employed (Smith *et al.*, 2009) in order to capture the lived transitionary experiences of this population and to explore the meanings participants may attribute to them. Following the completion of semi-structured interviews, data was transcribed and analysed within an IPA methodology framework. A total of sixteen super-ordinate themes were identified and incorporated into five master themes: *relationships with staff, lived experiences of transition, steps towards freedom, community embeddedness and different concepts of self*. Distribution of themes varied by participant and reflected the complexities of transitionary experiences. Further reflections upon each of the master themes and the context of these findings is presented below.

2.5.2 Context of Findings

The experiences and themes are conceptualised within the research and legislative contexts below. A number of the experiences and themes described can also be contextualised within models of offending including the Good Lives Model (Ward & Brown, 2004). As noted, within this strength-based model of offending behaviour the ten 'primary goods' represent the offenders' core needs and offending behaviour is conceptualised as an attempt to address

deficits in these core needs. Rehabilitative programmes and risk reduction must therefore include consideration of the core needs of the offender. Within the master themes some, but not all, of the primary goods were represented. This is in keeping with one of the fundamental underpinnings of the model which suggests that not all of these primary goods will be held in equal importance to offenders. Operationalisation of the model highlights the need to identify the primary goods that are most significant to the offender in order to identify what would constitute as a 'good life' and therefore reduce risk.

2.5.2.1 Reflections on Relationships with Staff

Within this master theme, participants' narratives highlighted the importance of their relationships with staff across health, social care and within the Criminal Justice System. In consideration of the Good Lives Model (Ward & Brown, 2004), this theme best represents the seventh identified primary good of 'relatedness'. Within this model relatedness represents connection to others including close and mutual bonds with important others such as partners, family members and friends. Within participants' narratives staff members were commonly represented as important others and participants reflected on the strengths and challenges of these relationships. The importance of 'therapeutic' relationships is well established within the general population (Ackerman & Hilsenroth, 2003). Within the forensic population, Ward and Brown (2004) highlight that the development of therapeutic relationships with staff is one of the key components of effective rehabilitation and should therefore be considered in treatment and in this case transition.

As discussed, duality was observed in participants' accounts, as relationships with staff were experienced as both supportive/ containing and supervisory/ restraining. These conflicting relationships represent the challenges in championing opposing goals and responding to different duties. This includes attempting to implement person-centred approaches to transition while remaining mindful of risk and public protection in the context of remaining restrictions within the Care Programme Approach (Department of Health, 2008a). At times staff were perceived as empathic and encouraging figures of care and containment, which is viewed as key in rehabilitative relationships with offenders (Marshall *et al.,* 2003). Simultaneously, staff were also viewed within their supervisory capacity and interpersonal relationships were viewed as punitive and restrictive. Similar narratives are presented within previous qualitative research with individuals with intellectual disabilities, which highlights issues of staff restrictions and the important distinction between care versus punishment (McNally *et al.,* 2007).

2.5.2.2 Reflections on Lived Experience of Transition

Within this master theme, superordinate themes of participants' lived experiences of transition included the emotional responses of fear, anxiety and worry. These provide a relevant context for some of the transitionary challenges highlighted in the aforementioned outcome based methodologies (Draine & Solomon, 1994; Keil *et al.*, 2008).

In contextualisation of these emotional responses, participants identified experiences of powerlessness in terms of lack of inclusion, choice and information. Issues of powerless can also be viewed within the context of the aforementioned restrictive relationships with staff. In consideration of the Good Lives Model (Ward & Brown, 2004), issues of choice and inclusion are clearly represented by the fifth identified primary good of 'excellence in agency'. Within this model agency primarily represents autonomy, encapsulating issues of personal choice and control. The representation of this primary good highlights its importance to participants, however participants' narratives reflected a perceived failure to be actively involved in decision making processes around transitions. Issues of lack of inclusion are in keeping with previous qualitative research with individuals with intellectual disabilities, which highlights issues of external control in the context of compulsory restrictions (McNally *et al.*, 2007).

Beyond active involvement, the perceived failure to achieve excellence in agency was also reflected in participants' accounts of lack of information regarding their transitions. This is best represented in the second primary good of 'knowledge' within the Good Lives Model (Ward & Brown, 2004). In this context the importance of knowledge is highlighted as the need to remain well informed in relation to things that are important to the individual. In this context, participants' suggested the need for more information in relation to their planned community placements. As discussed previously, in the completion of research the provision of information is fundamental to ethical considerations and issues of informed consent (Harris, 2003; Nind 2008). In clinical practice, when considering the needs of psychiatric

patients who remain subject to restrictions, the provision of information is identified as a key priority (Rogers *et al.,* 1993).

In addition to actively engaging service users in decision making and provision of information to achieve knowledge, participants also highlighted the needs for steps between when managing transitions. In clinical practice this is supported by recommended good practice when monitoring and managing issues of risk (Myers, 2004). One of the issues highlighted in the steps between was the experiences of delayed discharge. This issue is well documented within this vulnerable population (Mansell, 2010, Raina & Lunsky, 2010) and research highlights how this is in contravention of the Milan Principles outlined in the Mental Health (Care and Treatment) (Scotland) Act, (2003). Participants' experiences support the continuing issue of delays in transition. This is supported by recent research which highlights that significant delays in transitions between services continue to occur due to shortages in community resources and services (Mansell, 2010). This may also be reflective of the markedly diverse journeys of mentally disordered offenders through the Criminal Justice System and through health and social care pathways (Lindsay *et al.,* 2010).

2.5.2.3 Reflections on Steps Towards Freedom

Within this master theme, participants highlighted what they considered to be the different parts of their steps towards freedom. As with staff relationships, there was a sense of duality and conflict between the complex superordinate themes which represented an increase in

liberty occurring simultaneously with remaining restrictions. Similar to the previous master themes, experiences of increased control and autonomy are best represented by the fifth identified primary good of 'excellence in agency' within the Good Lives Model (Ward & Brown, 2004). Participants' experiences of increased autonomy and control suggest a service user defined level of successfulness of transition; particularly as such goals are at the core of the person-centred planning approaches (Department of Health, 2001a, Department of Health 2002; Scottish Executive, 2000a).

In addition to perceived increases in personal autonomy, participants also highlighted perceived increases in personal privacy. The importance participants attributed to personal privacy is supported by good practice guidelines for service users with intellectual disabilities which highlight that the personal privacy is fundamental to promoting dignity in healthcare (Royal College of Nursing, 2013). Personal privacy appeared to be interconnected to an increased sense of control and agency and participants' accounts also highlighted how this facilitated their relationships with family and friends. Similar issues have been reflected in previous qualitative research with forensic patients who identified the importance of personal privacy in maintaining intimate relationships with others (Quinn & Happell, 2015).

The simultaneous challenge of navigating the reality of remaining restrictions was also reflected within participants' accounts. Similar issues of ambivalence were echoed within participants' accounts of staff relationships. The tension between these two opposing goals is addressed within previous research which highlights the reality of balancing a need for

increased autonomy as part of person-centred framework with remaining legal restrictions and the need for public protection (Mansell, 2010).

2.5.2.4 Reflections on Community Embeddedness

Within this master theme, the importance of an emerging sense of community embeddedness was reflected within participants' accounts. The prominence of this theme in accounts suggests that participants' placed importance on community integration post transition. When considering issues of community embeddedness and social connectedness with individuals with intellectual disabilities, social isolation is a well-established concern (Emerson & Hatton, 1996). Following the marked shift from the pre-1970's culture of segregation and institutionalisation; individuals with intellectual disabilities have been increasingly supported in community settings (Department of Health, 1971). The deinstitutionalisation of individuals with intellectual disabilities has resulted in increasing importance being placed on community presence and integration. Prior to the development of the Good Lives Model, O'Brien & Tyne (1981) highlighted the 'Five Accomplishments' as a framework for social inclusion. These included both community 'presence' and community 'participation'.

Within the Good Lives Model, community embeddedness is best represented by the eighth identified primary good of 'community' (Ward & Brown, 2004). The importance of a sense of belonging to a group or community with shared interests, concerns or values is highlighted.

Ward and Brown (2004) emphasise that within the forensic population, attempts to obtain this primary good/ core need can be seen in individuals becoming associated with gangs or groups that hold anti-social values.

Within the superordinate themes, participants highlighted two significant parts of achieving community embeddedness which included both the importance of building relationships with others and the importance of engaging in work and meaningful activity. Regarding relationships with others, this directly represented in the Good Lives Model, within the aforementioned seventh identified primary good of 'relatedness' (Ward & Brown, 2004). Beyond the Good Lives Model participants' accounts are reflected within other forensic research, which highlights the importance of 'social capital' as a priority in probationary rehabilitative programmes (McNeill, 2009).

In consideration of the importance of work, participants' accounts are also directly represented in the Good Lives Model, within the fourth identified primary good of 'excellence in work' (Ward & Brown, 2004). Excellence relates to the opportunity to strive for mastery within a vocational context, including paid employment, volunteering opportunities or participation in other structured meaningful activities. In a forensic context, participants accounts were supported by the previous accounts of forensic mental health service users who highlighted the positive impact of vocational rehabilitation in improving mental health outcomes (McQueen & Turner, 2012). Participants' accounts were also supported by the previous accounts of individuals with intellectual disabilities who highlighted the

positive impact of supported employment in providing structure and also in providing participatory experiences leading to an increased sense of social integration and community embeddedness (Cramm *et al.,* 2009). Within the latter study, participants also highlighted the importance of feeling valued and appreciated which is likely to impact on service users sense of self.

2.5.2.5 Reflections on Different Concepts of Self

Within this master theme, participants reflected on their different concepts of self. Similar to previous representations of duality in staff relationships and steps towards freedom, participants also reflected upon two conflicting self-identities, self as a 'forensic service user' or 'offender' versus new identities emerging following the transition period, fostered through community relationships and vocational opportunities. Participants' accounts of feeling burdened or hindered by remaining restrictions and discussions regarding risk suggested a desire to move away from old 'offender' identities and is represented within stigma research. High levels of experienced stigma, perceived stigma and self-stigma are widely reported by mental health patients (Thornicroft *et al.,* 2007), individuals with intellectual disabilities (Ali *et al.,* 2012) and offender populations (Mezey *et al.,* 2016).

Within models of offending, the significance of stigma and emergence of new identities is also contextualised within the Good Lives Model. Ward and Brown (2004) highlight the importance of enabling continuity between old identities and new, emergent identities rather

than making assumptions of previous anti-social values and identities which can result in ineffective and poorly targeted treatment approaches (Willis *et al.,* 2013). In contrast to previous models of offending, it is asserted that continuity can be achieved by assuming that individuals core values and commitments remain the same, however the means by which they can obtain their primary goods is changed (Ward & Brown, 2004).

2.5.3 Limitations of Current Study

A number of limitations were identified in relation to the current study. While steps were taken during the recruitment process to ensure informed consent (Harris, 2003; Nind 2008), recruitment via care providers presented a several challenges. Reliance upon care providers to identify appropriate participants protected the rights and privacy of service users, but lack of direct access to the sample resulted in a lengthy and time consuming recruitment process. In attempting to support informed consent, the presence of a staff member was required when initial meetings were arranged between the researcher and potential participants and this presented a number of logistical challenges and added to the length of the recruitment process.

Given the constraints of the current study and logistical challenges in recruitment a smaller sample was recruited than was initially anticipated and this remains a limitation of the current study. It is noted that qualitative methodologies such as IPA suggest that a smaller sample size is recruited in order to enable more in-depth analysis of individual participants'

experiences. Due to the commitment to individual experiences, qualitative methodologies do not include the use of power calculations with a focus on the 'existence of experiences over the incidence of experiences' (Smith *et al.,* 2009). While the required sample size is to be considered on a case by case basis, guidelines have suggested between four – ten participants for postgraduate research (Smith *et al.,* 2009) and between six – eight participants when the study is being completed by a novice IPA researcher (Smith & Eatough, 2007). While the current study did fall within the aforementioned guidelines, issues of homogeneity could have been better addressed with access to a larger target population.

As discussed, in keeping with the methodological principles of IPA, purposeful sampling was employed in order to recruit as homogeneous a sample as was practicable within the confines of the current study (Patton, 2002; Suri, 2011). As such, within the current study, homogeneity of sample was achieved across particular variables. All participants had a diagnosed intellectual disability, all participants were supported by a specialist FLDS and all participants had been through the Criminal Justice System. Additionally, all participants had transitioned from inpatient secure settings to community based services and remained in the community following this transition.

It is noted that individuals with intellectual disabilities represent a particularly heterogeneous group (Talbot, 2008) and similar limitations present when attempting to recruit a homogeneous sample within the forensic population. Within a purposeful sampling framework, Smith *et al.,* (2009) suggest that homogeneity within sample populations should

be achieved by filtering potential participants by characteristics in relation to the research questions. Given the specificity of the research question, within the current study it was not possible to achieve homogeneity across certain factors including the nature of index offences and the level of remaining restriction. In particular, the constraints of the current study and logistics of recruitment resulted in variation in the time since transition across the sample, ranging from 2-11 years. As a result, there were differences in the amount of time that participants had spent in the community and this is likely to have impacted on their sense of becoming embedded in communities and forging new identities. Additionally, there was variation in the secure services that participants transitioned from, which included secure hospital settings and secure schooling settings.

In considering the implications of homogeneity on the overall generalisability of findings, it is noted that given the commitment to individual experiences, IPA research does not seek to achieve an objective and generalizable 'truth'. Instead, IPA seeks to explore and highlight the experiences of individuals and the meaning they may attribute to them (Smith *et al.*, 2009). To this end, the current study does not seek to provide findings which are objectively generalizable to the wider forensic population, or the wider population of individuals with intellectual disabilities. However, the findings of the current study do represent rich and detailed accounts of the transitionary experiences of offenders with intellectual disabilities. The stages, relationships, supports, perceptions, accomplishments and remaining challenges explored are all theoretically relevant in supporting transitions with this population and in highlighting areas of development in research and clinical practice.

2.5.4 Research Implications

One of the main implications for future research demonstrated by the richness of participant accounts is the need to actively engage individuals with intellectual disabilities in research. The quality of the data obtained in the current study is testament to the insight that can be achieved in involving service users in *their own* research to prevent overdependence on staff accounts (Gildberg *et al.,* 2010). This has also been evidenced in previous research which actively engages this population (Woods *et al.,* 2008). Aside from the quality of data achieved, there is also a moral and ethical obligation to actively engage offenders with intellectual disabilities in the research process (Goodwin *et al.,* 1991). This can be achieved by adapting and evolving traditional research methodologies which have previously 'alienated' this population (Oliver, 1992). The need for exploration of further qualitative methodologies is demonstrated in serving to address the gaps in the literature and understanding of the needs of offenders by allowing service users to define and prioritise their experiences on their own terms (Hollomotz, 2014).

The current research also highlights the need to develop and adapt post-transition outcome measures to better suit the current culture of person-centred care. In the context of emerging strength-based models of offending behaviour including the Good Lives Model (Ward & Brown, 2004), future research could explore developing new post-transition quality of life measures that include a measure of the 'primary goods' which offenders prioritise for themselves. Given that some, but not all of the primary goods were represented in

participants accounts in the current study, additional research may seek to explore which primary goods offenders may tend to prioritise and how these relate to post-transition outcomes. Combining both qualitative and quantitative methodologies could explore the relationship between prioritised primary goods and traditional post-transition 'success' indicators such as rates of recidivism, vocational outcomes, social capital and mental health.

In order to address limitations of homogeneity of sample, future qualitative research could aim to achieve greater specificity in exploring the transitionary experiences by investigating the experiences of individuals from different services separately. Additionally, given the variation in time since transition, future research may also seek to explore longitudinal effects and the impact of remaining restrictions. In relation to future samples, as the current study did not recruit any female offenders, it may also be beneficial to explore the experiences of female offenders in terms of transitionary experiences and their journey through the Criminal Justice System (Myers, 2004).

2.5.5 Professional Practice Implications

In consideration of professional practice implications, the current research supports the need to employ new more holistic, strength-based models of offending behaviour such as the Good Lives Model (Ward & Brown, 2004). Given the richness of data and insights provided, the need to actively engage service users in their own transition goals is evident. The Good Lives Model can be utilised to assist service users to prioritise goals regarding post-transition

outcomes and post-transition functioning. This is in keeping with concurrent professional practice recommendations, which highlight the need for collaborative working with offender in identifying appropriate treatment goals and developing more robust therapeutic alliances (Mann & Shingler, 2006).

In addition to identifying post-transition goals, the need to involve service users in measuring the 'successfulness' of their transitions is also demonstrated. Traditional clinical indicators of success such as rates of recidivism (MacCulloch & Bailey, 1991), psychiatric symptomatology (Royal College of Psychiatrists, 2013) must be combined with service user accounts based upon their own experiences of transition. This is supported within wider clinical practice recommendations which highlight the need to routinely identify and consider patient experiences as part of considering the effectiveness of treatment outcomes (Department of Health, 2008b). Consideration of services users' views should continue to be facilitated within the Care Programme Approach (Department of Health, 2008a).

The current research also serves to support the continued development of community-based services and community-based rehabilitation models (Reed Report, 1992; Scottish Executive 2004). Given the importance of issues of community embeddedness and social integration highlighted, future community sentences and services must provide positive opportunities for social and vocational achievement (Bradley Report, 2009).

Examination of individual participants' accounts suggests the need for additional provision of information (Rogers *et al.*, 1993) and the need to more actively involve service users in overall transition planning and the steps between (Myers, 2004). The continued presence of delayed discharges in participants' accounts highlights the need to consider further development of community services to address 'gaps' in the service provision (Mansell, 2010). This also suggests the continuing need for clinical practice to adhere to the Millan Principles outlined in the Mental Health (Care and Treatment) (Scotland) Act, (2003).

2.5.6 Conclusions

The current study provided a rich and detailed account of the transitionary experiences of offenders with intellectual disabilities, with a particular focus on the transition from inpatient secure services to community based services. In keeping with recent developments in models of offending behaviour, the use of qualitative methodology allowed participants to identify and reflect upon various significant parts of their transitionary experiences and the meaning they attributed to them.

Participants' accounts highlighted a number of salient themes including both the significance and ambivalence of staff relationships, the diversity in lived experiences of transitions, the tentative steps towards freedom, the importance of a sense of embeddedness in wider communities and finally the implications of the above in relation to different concepts of self. The successful engagement of a doubly marginalised population in the research process,

primarily highlights the moral and ethical need for continued active engagement of this population in future research.

The richness of accounts also provide support for continued use and development of newer strength-based models of offending behaviour. The importance of social integration and vocational opportunities provide support to community-based services and community-based models of rehabilitation. Finally, participants' accounts in the current study support the need for clinical practice development in how we assess, support and achieve 'successful' transitions with this vulnerable population.

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APPENDIX 1: AUTHOR GUIDELINES – Journal of Applied Research in Intellectual Disabilities

Author Guidelines

1. GENERAL

The *Journal of Applied Research in Intellectual Disabilities* is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

Please read the instructions below carefully for details on submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication. Authors are encouraged to visit http://authorservices.wiley.com/bauthor/ for further information on the preparation and submission of articles. All manuscripts must be submitted solely to this journal and not published, in press, or submitted elsewhere.

2. ETHICAL GUIDELINES

Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Please see Section 2.2 below.

2.1 Authorship and Acknowledgements

Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL authors must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship.

It is a requirement that all authors have been accredited as appropriate under submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

Acknowledgements: Under Acknowledgements please specify contributors to the article other than the authors accredited. Please also include specifications of the source of funding for the study and any potential conflict of interest if appropriate. Suppliers of materials should be named and their location (town, state/county, country) included.

2.2 Ethical Approvals

Research involving human participants will only be published if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (version, 2002 www.wma.net) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant (or the participant's representative, if they lack capacity), and according to the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included.

All studies using human participants should include an explicit statement in the Material and Methods section identifying the review and ethics committee approval for each study, if applicable. Editors reserve the right to reject papers if there is doubt as to whether appropriate procedures have been used.

Ethics of investigation: Papers not in agreement with the guidelines of the Helsinki Declaration as revised in 1975 will not be accepted for publication.

2.3 Clinical Trials

Clinical trials should be reported using the CONSORT guidelines available at www.consort-statement.org. A CONSORT checklist should also be included in the submission material (www.consort-statement.org).

The *Journal of Applied Research in Intellectual Disabilities* encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public trials registries: www.clinicaltrials.org, www.isrctn.org. The clinical trial registration number and name of the trial register will then be published with the paper.

2.4 Conflict of Interest and Source of Funding

Conflict of Interest: Authors are required to disclose any possible conflict of interest. These include financial (for example patent ownership, stock ownership, consultancies, and speaker's fee). Author's conflict of interest (or information specifying the absence of conflict of interest) will be published under a separate heading.

The *Journal of Applied Research in Intellectual Disabilities* requires that sources of institutional, private and corporate financial support for the work within the manuscript must be fully acknowledged, and any potential conflict of interest noted. As of 1st March 2007, this information is a requirement for all manuscripts submitted to the journal and will be published in a highlighted box on the title page of the article. Please include this

information under the separate headings of 'Source of Funding' and 'Conflict of Interest' at the end of the manuscript.
If the author does not include a conflict of interest statement in the manuscript, then the following statement will be included by default: 'No conflict of interest has been declared'.

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4. SUBMISSION OF MANUSCRIPTS

Submissions are now made online using ScholarOne Manuscripts (formerly Manuscript Central). To submit to the journal go to http:// mc.manuscriptcentral.com/jarid. If this is the first time you have used the system you will be asked to register by clicking on 'create an account'. Full instructions on making your submission are provided. You should receive an acknowledgement within a few minutes. Thereafter, the system will keep you informed of the process of your submission through refereeing, any revisions that are required and a final decision.

4.1 Manuscript Files Accepted

Manuscripts should be uploaded as Word (.doc) or Rich Text Format (.rft) files (not write-protected) plus separate figure files. GIF, JPEG, PICT or Bitmap files are acceptable for submission, but only high-resolution TIF or EPS files are suitable for printing.
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2. Figure files under the file designation 'figures'.
3. Title page which should include title, authors (including corresponding author contact details), acknowledgements and conflict of interest statement where applicable, should be uploaded under the file designation 'title page'.

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5. MANUSCRIPT TYPES ACCEPTED

Original Articles, Review Articles, Brief Reports, Book Reviews and ***Letters to the Editor*** are accepted. ***Theoretical Papers*** are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies

are welcomed. Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.

6. MANUSCRIPT FORMAT AND STRUCTURE

6.1 Format

Language: The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found athttp://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

6.2 Structure

All manuscripts submitted to the *Journal of Applied Research in Intellectual Disabilities* should include:

Cover Page: A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.

Running Title: A short title of not more than fifty characters, including spaces, should be provided.

Keywords: Up to six key words to aid indexing should also be provided.

Main Text: All papers should have a structured abstract (maximum 150 words) as follows: Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study. Authors should make use of headings within the main paper as follows: Introduction, Method, Results and Discussion. Subheadings can be used as appropriate. All authors must clearly state their research questions, aims or hypotheses clearly at the end of the Introduction. Figures and Tables should be submitted as a separate file.

Style: Manuscripts should be formatted with a wide margin and double spaced. Include all parts of the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:

-Include all figure legends, and tables with their legends if available.

-Do not use the carriage return (enter) at the end of lines within a paragraph.

-Turn the hyphenation option off.

-In the cover email, specify any special characters used to represent non-keyboard characters.

-Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).
-Use a tab, not spaces, to separate data points in tables.
-If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.
Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

6.3 References

The reference list should be in alphabetic order thus:
-Emerson E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities*. Cambridge University Press, Cambridge.
-McGill P. & Toogood A. (1993) Organising community placements. In: *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services* (Eds E. Emerson, P. McGill & J. Mansell), pp. 232-259. Chapman and Hall, London.
-Qureshi H. & Alborz A. (1992) Epidemiology of challenging behaviour. *Mental Handicap Research* 5, 130-145
Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown *et al*. 1977). Authors are responsible for the accuracy of their references.

We recommend the use of a tool such as EndNote or Reference Manager for reference management and formatting.
EndNote reference styles can be searched for here:
http://www.endnote.com/support/enstyles.asp
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http://www.refman.com/support/rmstyles.asp
The Editor and Publisher recommend that citation of online published papers and other material should be done via a DOI (digital object identifier), which all reputable online published material should have - see www.doi.org/ for more information. If an author cites anything which does not have a DOI they run the risk of the cited material not being traceable.

6.4 Tables, Figures and Figure Legends

Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, and given a short caption.

Figures should be referred to in the text as Figures using Arabic numbers, e.g. Fig.1, Fig.2 etc, in order of appearance. Figures should be clearly labelled with the name of the first author, and the appropriate number. Each figure should have a separate legend; these should be grouped on a separate page at the end of the manuscript. All symbols and abbreviations should be clearly explained. In the full-text online edition of the journal, figure legends may be truncated in abbreviated links to the full screen version. Therefore, the first 100 characters of any legend should inform the reader of key aspects of the figure.

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Although low quality images are adequate for review purposes, print publication requires high quality images to prevent the final product being blurred or fuzzy. Submit EPS (line art) or TIFF (halftone/photographs) files only. MS PowerPoint and Word Graphics are unsuitable for printed pictures. Do not use pixel-oriented programmes. Scans (TIFF only) should have a resolution of at least 300 dpi (halftone) or 600 to 1200 dpi (line drawings) in relation to the reproduction size. Please submit the data for figures in black and white or submit a Colour Work Agreement Form. EPS files should be saved with fonts embedded (and with a TIFF preview if possible).
Further information can be obtained at Wiley-Blackwell's guidelines for figures:http://authorservices.wiley.com/bauthor/illustration.asp.
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7. AFTER ACCEPTANCE
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APPENDIX 2: TABLE OF EXCLUDED PAPERS

Study	Reason(s) for exclusion
Bell, L. (2009)	Select sample by type of offence and time left to serve
Birmingham *et al.,* (1998)	Only included follow up information in relation to original data presented in previous study (Birmingham *et al.,* 1996 – included in current review)
Birmingham *et al.,* (2000)	Did not include measure of ID in study
Brooke *et al.,* (1996)	Journal article covering Maden *et al.* (1996) data
Cunniffe *et al.,* (2012)	Select sample by sentence length/ only included general interviews
Davidson *et al.,* (1995)	Only reported IQ as <80
Gavin *et al*., (2003)	Select sample by specific screening questions e.g. by offence
Glaser & Deane (1999)	Australian sample
Glaser & Florio (2004)	Australian sample
Gunn *et al.,* (1991)	Journal article covering Gunn *et al.,* (1991) data
Hassiotis *et al.,* (2011)	Only used data drawn from Singleton *et al.* (1998)
Henderson, C. (2004)	Focus on young offenders aged 17-19 years old only no adult sample
Herrington, V. (2009)	Select sample of 18-21 year old prisoners only, with no adult sample
Herrington, V. (2011)	Select sample of 18-21 year old prisoners only, with no adult sample
HM Inspectorate of Probation/ HM Inspectorate of Prison (2015)	Provided review and recommendations for current screening procedures only, no prevalence data collected
Hogue *et al*., (2006)	High security inpatient sample
Langevin & Curnoe (2008)	United States community sample
Loucks, N. (2007)	Provides review of literature only
McKenzie *et al.,* (2012)	Assessing validity of ID screening tool only
Mason, J. (1998)	Only included offenders in the community on probation
Mason & Murphy (2002a)	Included probation only sample
Mason & Murphy (2002b)	Community LD service and unemployment service sample
Mudoch, N. (2008)	Select sample of >55 year old prisoners
Murphy *et al.,* (2000)	Only collected data from within the Republic of Ireland
Myres, F. (2004)	Asked prison staff to complete pro-forma re: numbers of prisoners with formal diagnosis housed in prison Did not include any direct assessment measures in prison sample
Parsons *et al.,* (2001)	Did not include measure of ID in study
Rack (2005)	Focus of study on learning difficulties i.e. dyslexia, reported IQ scores as <85 only using one WAIS-R subtest
Rice, M.E. (1999)	Only included specific measures of reading and attentional ability only
Salekin *et al.,* (2010)	Provides review of literature only, no prevalence data collected
Schretlen & Arkowitz (1990)	Did not include measure of ID in study
Smith *et al.,* (1996)	Did not include diagnosis of ID in study
Veneziano & Veneziano (1996)	Relied upon surveys of prison staff for estimates of prevalence only
Vinkers *et al.,* (2011)	Sample of Dutch pre-trial defendants

APPENDIX 3: PREVALENCE CRITICAL APPRAISAL INSTRUMENT (Munn *et al., 2014)*

The 10 criteria used to assess the methodological quality of studies reporting prevalence data and an explanation are described below. These questions can be answered either with a yes, no, unclear, or not applicable. **Answers: Yes, No, Unclear or Not/Applicable**

Criteria 1. Was the sample representative of the target population?

Notes from Munn *et al.* (2014) - This question relies upon knowledge of the broader characteristics of the population of interest. If the study is of women with breast cancer, knowledge of at least the characteristics, demographics, and medical history is needed. The term "target population" should not be taken to infer every individual from everywhere or with similar disease or exposure characteristics. Instead, give consideration to specific population characteristics in the study, including age range, gender, morbidities, medications, and other potentially influential factors. For example, a sample may not be representative of the target population if a certain group has been used (such as those working for one organisation, or one profession) and the results then inferred to the target population (i.e. working adults).

Notes relating to the current review – For the current review the sample was deemed to be representative of the target population if it included adult prisoners, age 16 years upwards, male and/or female, including either or both sentenced/ remand prisoners. The sample was deemed not to representative of the target population if for example: the study only included one prison which only housed one specific type of offender e.g. prisoners who had committed sexual offences, if the study focused solely on a select area/ wing of a prison, if the study focused solely on one type of offender or if the study only sampled prisoners who were referred for psychiatric assessment and treatment.

Criteria 2. Were study participants recruited in an appropriate way?

Notes from Munn *et al.* (2014) - Recruitment is the calling or advertising strategy for gaining interest in the study, and is not the same as sampling. Studies may report random sampling from a population, and the methods section should report how sampling was performed. What source of data were study participants recruited from? Was the sampling frame appropriate? For example, census data is a good example of appropriate recruitment as a good census will identify everybody. Was everybody included who should have been included? Were any groups of persons excluded? Was the whole population of interest surveyed? If not, was random sampling from a defined subset of the population employed? Was stratified random sampling with eligibility criteria used to ensure the sample was representative of the population that the researchers were generalizing to?

Notes relating to the current review - For the current review recruitment was deemed to be appropriate if, for example: participants were randomly selected from the current prison population, or if screening and assessment was performed upon entry to the prison across a number of days. Recruitment was deemed to be inappropriate if, for example: certain groups of prisoners were excluded such as prisoners in higher security wings, prisoners who were serving shorter sentences or prisoners who were receiving psychiatric assessment and treatment.

Criteria 3. Was the sample size adequate?

Notes from Munn *et al.* (2014) - An adequate sample size is important to ensure good precision of the final estimate. Ideally we are looking for evidence that the authors conducted a sample size calculation to determine an adequate sample size. This will estimate how many subjects are needed to produce a reliable estimate of the measure(s) of interest. For conditions with a low prevalence, a larger sample size is needed. Also consider sample sizes for subgroup (or characteristics) analyses, and whether these are appropriate. Sometimes, the study will be large enough (as in large national surveys) whereby a sample size calculation is not required. In these cases, sample size can be considered adequate.

When there is no sample size calculation and it is not a large national survey, the reviewers may consider conducting their own sample size analysis using the following formula: n=Z2P (1−P) d2 - Where: n= sample size, Z= Z statistic for a level of confidence, P= Expected prevalence or proportion (in proportion of one; if 20%, P= 0.2), d= precision (in proportion of one; if 5%, d= 0.05).

Notes relating to the current review – For the current review, when there was no sample size calculation reported, sample size analysis was completing using the above sample size formulation for prevalence studies reported by Naing *et al.,* (2006). This sample size was calculated using the online version of the above formula, retrieved August 2015 (Naing *et al.,* 2015*).* If the reported sample size was found to meet the normal approximation assumption (Daniel, 1999) at a precision level of 0.05 then the sample size was deemed to be adequate.

Criteria 4. Were the study subjects and setting described in detail?

Notes from Munn *et al.* (2014) - Certain diseases or conditions vary in prevalence across different geographic regions and populations (e.g. women vs. men, socio-demographic variables between countries). Has the study sample been described in sufficient detail so that other researchers can determine if it is comparable to the population of interest to them?

Notes relating to the current review - For the current review the study subjects and settings were described in adequate detail if basic information around the prison from which the sample was drawn. This would allow for comparison of basic geographic and sociodemographic variables and access to information in relation to previous and current screening/ assessment procedures as required.

Criteria 5. Is the data analysis conducted with sufficient coverage of the identified sample?

Notes from Munn *et al.* (2014) - A large number of dropouts, refusals or "not founds" amongst selected subjects may diminish a study's validity, as can low response rates for survey studies.

- Did the authors describe the reasons for non-response and compare persons in the study to those not in the study, particularly with regards to their socio-demographic characteristics?

- Could the not-responders have led to an underestimate of prevalence of the disease or condition under investigation?

- If reasons for non-response appear to be unrelated to the outcome measured and the characteristics of non-responders are comparable to those in the study, the researchers may be able to justify a more modest response rate.

- Did the means of assessment or measurement negatively affect the response rate (measurement should be easily accessible, conveniently timed for participants, acceptable in length, and suitable in content).

Notes relating to the current review – For the purposes of the current review analysis was deemed to have been conducted with sufficient coverage if, for example: there was not a large number of reported drop outs or refusals, and if any adequate reasons were given for any drop-outs or refusals such as a number of non-English speaking participants for whom the assessment measures used would not have been appropriate. Analysis was assumed not to have sufficient coverage if, for example: drop-outs or refusals were completely unaccounted for or if the reported descriptions of non-responders may have led to an underestimate of prevalence, such as potentials participants level of literacy meaning that they were unable to access consent forms.

Criteria 6. Were objective, standard criteria used for measurement of the condition?

Notes from Munn *et al.* (2014) - Here we are looking for measurement or classification bias. Many health problems are not easily diagnosed or defined and some measures may not be capable of including or excluding appropriate levels or stages of the health problem. If the outcomes were assessed based on existing definitions or diagnostic criteria, then the answer to this question is likely to be yes. If the outcomes were assessed using observer reported, or self-reported scales, the risk of over- or under-reporting is increased, and objectivity is compromised. Importantly, determine if the measurement tools used were validated instruments as this has a significant impact on outcome assessment validity.

Notes relating to the current review – For the current review objective, standard criteria were only deemed to have been used if studies attempted to collect and explicitly reported assessment or screening information in relation to all three diagnostic criteria an individual must meet in order to be diagnosed with an intellectual disability: (British Psychological Society, 2001; ICD-10: World Health Organisation, 1992).

- significant impairment of intellectual functioning (evidenced by an IQ < 70)
- significant impairment of adaptive/ social functioning
- onset of the above difficulties during the developmental phased (prior to the age of 18years)

Criteria 7. Was the condition measured reliably?

Notes from Munn *et al.* (2014) - Considerable judgment is required to determine the presence of some health outcomes. Having established the objectivity of the outcome measurement instrument (see item 6 of this scale), it is important to establish how the measurement was conducted. Were those involved in collecting data trained or educated in the use of the instrument/s? If there was more than one data collector, were they similar in terms of level of education, clinical or research experience, or level of responsibility in the piece of research being appraised? - Has the researcher justified the methods chosen? - Has the researcher made the methods explicit? (For interview method, how were interviews conducted?)

Notes relating to the current review - For the current review the condition (intellectual disabilities) was only deemed to have been measured reliably if all three of the above criteria were each assessed using validated and standardised assessment measures as outlined within the main body of the review.

Criteria 8. Was there appropriate statistical analysis?

Notes from Munn *et al.* (2014) - As with any consideration of statistical analysis, consideration should be given to whether there was a more appropriate alternate statistical method that could have been used. The methods section should be detailed enough for reviewers to identify the analytical technique used and how specific variables were measured. Additionally, it is also important to assess the appropriateness of the analytical strategy in terms of the assumptions associated with the approach as differing methods of analysis are based on differing assumptions about the data and how it will respond. Prevalence rates found in studies only provide estimates of the true prevalence of a problem in the larger population. Since some subgroups are very small, 95% confidence intervals are usually given.

Notes relating to the current review - For the current review the statistical analysis was deemed to be appropriate if a clear estimate of prevalence and number of individual's identified was reported in relation to the overall sample and any assumptions made on the basis of the reported prevalence are deemed to be appropriate. Statistical analysis was deemed to be inappropriate if the study failed to report a clear estimate of prevalence, number of individuals or made inappropriate assumptions based upon the reported prevalence.

Criteria 9. Are all important confounding factors/ subgroups/differences identified and accounted for?

Notes from Munn *et al.* (2014) - Incidence and prevalence studies often draw or report findings regarding the differences between groups. It is important that authors of these studies identify all important confounding factors, subgroups and differences and account for these.

Notes relating to the current review – For the current review studies were only deemed to have met this criteria if they clearly reported information in relation to assessment/ screening and incidence of all confounding factors/ subgroups and differences. For the current condition these include: age, gender, level of IQ (if reported, presence of alcohol and substance misuse, presence of head injury and presence of psychiatric comorbidity.

Criteria 10. Were subpopulations identified using objective criteria?

Notes from Munn *et al.* (2014) - Objective criteria should also be used where possible to identify subgroups (refer to question 6).

Notes relating to the current review – For the current review studies were only deemed to have met this criteria if they assessed and reported the above information (question 9) using objective criteria. For example: this may include an attempt to identify the above confounding factors and subgroups based upon current diagnostic criteria through use of validated and reliable assessment or screening measures.

APPENDIX 4: CONFIRMATION OF R&D APPROVAL

Research and Development

Foresterhill House Annexe
Foresterhill
ABERDEEN
AB25 2ZB

Miss Gillian Grieve
NHS Grampian
Psychology Department
Elmwood
Ashgrove Road
Aberdeen
AB25 3BW

Date 27/05/2014
Project No 2013PC009

Enquires to Lynn Massie
Extension 53846
Direct Line 01224 553846
Email grampian.randdpermissions@nhs.net

Dear Miss Grieve

Management Permission for Non-Commercial Research

STUDY TITLE: An exploration of the experiences of offenders with learning difficulties within a specialist Forensic Learning Disability service in Scotland.

PROTOCOL NO: V3 - 20 April 2014
REC REF: 13/NS/0122

Thank you very much for sending all relevant documentation. I am pleased to confirm that the project is now registered with the NHS Grampian Research & Development Office. The project now has R & D Management Permission to proceed locally. This is based on the documents received from yourself and the relevant Approvals being in place.

All research with an NHS element is subject to the Research Governance Framework for Health and Community Care (2006, 2nd edition), and as Chief or Principal Investigator you should be fully committed to your responsibilities associated with this.

It is particularly important that you inform us when the study terminates.

The R&D Office must be notified immediately and any relevant documents forwarded to us if any of the following occur:

- A change of Principal Investigator, Chief Investigator or any additional research personnel
- Premature project termination
- Any amendments – substantial or non-substantial (particularly a study extension)

- Any change to funding or any additional funding

We hope the project goes well, and if you need any help or advice relating to your R&D Management Permission, please do not hesitate to contact the office.

Yours sincerely

Susan Ridge
Non-Commercial Manager

c.c. Dr Ethel Quayle

Sponsor: Edinburgh University

APPENDIX 5: CONFIRMATION OF NRES APPROVAL

NRES Committees - North of Scotland
Summerfield House
2 Eday Road
Aberdeen
AB15 6RE
Telephone: 01224 558458
Facsimile: 01224 558609
Email: nosres@nhs.net

22 May 2014

Miss Gillian Grieve
Trainee Clinical Psychologist
NHS Grampian
Clinical Psychology
Elmwood
Ashgrove Road
ABERDEEN
AB25

Dear Miss Grieve

Study title: An exploration of the experiences of offenders with learning disabilities within a specialist Forensic Learning Disability service in Scotland.
REC reference: 13/NS/0122
Amendment number: AM01
Amendment date: 21 May 2014
IRAS project ID: 128190

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion
The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents
The documents reviewed and approved at the meeting were:
Document Version Date
Notice of Substantial Amendment (non-CTIMP) AM01 21 May 2014
Staff Information Sheet 5 25 April 2014
Protocol 3 20 April 2014
Interview Schedule 5 22 April 2014
Participant consent form 8 25 April 2014
Participant information sheet (PIS): OP & IP 8 22 April 2014
Summary CV for Chief Investigator (CI) 21 May 2014

Membership of the Committee
The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval
All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.
We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/
13/NS/0122: Please quote this number on all correspondence
Yours sincerely

Professor Helen Galley
Chair

Enclosures: List of names and professions of members who took part in the review
Copy to: University of Aberdeen
Ms Marianne Laird

NRES Committees - North of Scotland
Summerfield House
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Telephone: 01224 558474
Facsimile: 01224 558609
Email: nosres@nhs.net

NHS
Grampian

30 September 2013

Miss Gillian Grieve
Trainee Clinical Psychologist
Forensic Learning Disability Service
Elmwood
Ashgrove Road,
ABERDEEN
AB253BW

Dear Miss Grieve

Study title:	**An exploration of the experiences of offenders with learning disabilities within a specialist Forensic Learning Disability service in Scotland.**
REC reference:	**13/NS/0122**
IRAS project ID:	**128190**

The Research Ethics Committee reviewed the above application at the meeting held on 26 September 2013.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Scientific Officer Dr Rachel Venables, nosres@nhs.net.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

Thank you for attending the meeting and clarifying the following points.

- The Committee were unclear about the capacity of the potential participants to give consent and how the researcher would confirm that they had this capacity. You replied that Individuals would be identified as users of the Learning Disabilities Service, their needs would be known and assessed and the inclusion criteria for the study would be those who had a high/moderate learning disability. You informed the Committee that the cognitive capacity of the individual was recorded on the HCR20 form. The HCR20 form would also have background information about the individual.

- The Committee asked why a witness was being included in the Consent Process. You replied that this was on the advice of the University of Edinburgh.

- The Committee asked where the interviews would take place and had concerns if it was in a public setting. You informed the Committee that the potential participants would be living in community supported accommodation and there would be support available.

- The Committee asked if it was relevant to contact the participants GP. You replied that this was on the advice of the University of Edinburgh but if the reflections/discussion that took place during the study might have effects on the participants they might require medical interventions. The Committee felt that as the study was not changing the participant's medical care then it was not necessary to contact the GP but would respect the advice of the University and you.

- The Committee noted that a Pilot Study was planned and asked what this would involve. You informed the Committee that the Pilot Study would take place at Elmwood and it would include 1 client. The client would be taken through the written literature and the interview questions. Any changes or alterations would then be made.

- The Committee congratulated you on putting together a comprehensive Participant Information Sheet for this participant group and appreciated that some points would be discussed verbally. The Committee felt that there was still too much writing on the Information Sheet for example on Page 2 regarding 'If you say yes - Fill in the taking part form on page 6'. You replied that the Information Sheet had been discussed with the Learning Disabilities Service and Speech and Language Therapy and would meet with staff to discuss the Information Sheets before they were distributed and any changes would be made at this stage. The Committee asked that any changes to the Information Sheets be forwarded to the Committee for review. The researcher agreed to this.

- The Committee felt that as this was a student research project, the Supervisor's details should be included on the Participant Information Sheet as a point of contact. You agreed to this.

- The Committee asked why generic help lines had been added to the Information Sheet and not help lines that were specific for learning difficulties'/learning disabilities. You replied that all the ones that were listed were accessible 24 hours a day and the participants would have no issues accessing these services.

- The Committee asked what local support was in place for the researcher. You replied that weekly meetings would be held with the local supervisor - Amanda Mackenzie.

- The Committee noted that data was to be stored on laptop and home computers. The Committee informed the researcher that the primary data source should not be stored on a laptop computer and if data was to be stored on a laptop it should be anonymised. You agreed to this.

- The Committee asked how the researcher would access the participants. You replied that Amanda Mackenzie would access the HCR20 forms (as part of her current role) and identify suitable candidates.

- The Committee asked how you would deal with Recall Bias. YOu replied that the main focus of the study was the experience within the service and the analysis of the data would be reflective but the researcher acknowledged this may be an issue.

Additional Conditions

- Please provide a modified Participant Information Sheet, based on the comments in the above discussion.

- The Committee felt that the GP does not need to be informed about the participation of the patient but were happy for this to be left in.

- A36 - Please provide assurances that no identifiable data will be stored on laptop computers.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter		04 September 2013
Interview Schedules/Topic Guides	4	11 July 2013
Investigator CV – Gillian Grieve		04 September 2013
Supervisor's CV: Karen McKenzie		18 July 2013
GCP Non-Drug Trials - Certificate		14 September 2012
Email From Roelf Dijkhuizen		27 August 2013
Safety Protocol for Participant Interviews	2	07 May 2013
Distress Protocol for Participant Interviews	3	11 July 2013
Helplines for Support	3	14 June 2013
GP Letter	1	08 May 2013
Participant Consent Form	7	10 July 2013
Participant Information Sheet: Staff	3	10 July 2013
Participant Information Sheet: PIL - IP	6	10 July 2013
Participant Information Sheet: PIL - OP	6	10 July 2013
Protocol	2	11 July 2013
REC application	128190/497157/1/236	05 September 2013
Referees or other scientific critique report		05 August 2013

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/NS/0122	**Please quote this number on all correspondence**

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

KGood

PP **Dr Alex Johnstone**
Chair

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
"After ethical review -- guidance for researchers"

Copy to: Ms Marianne Laird
Professor David Reid, NHS Grampian Research & Development

APPENDIX 6: STAFF INFORMATION SHEET

REC: 13/NS/0122 R&D: 2013PC009
IRAS: 128190 Version Number & Date: SI5 – 25.04.14
Project: Exploring the experiences of service users in a specialist Forensic Learning Disability Service.
Principal Researcher: Gillian Grieve, Trainee Clinical Psychologist

NHS Grampian

STAFF INFORMATION SHEET

Services users you are currently supporting are being invited to take part in a research study. In order to help support them participate in this study please read this information.

Purpose of the Study

This study is designed to explore the transition experiences of service users within Forensic Learning Disability Service (FLDS). This will include both inpatient and (community) out patients. It is hoped that by understanding more about service users experiences it will be possible to work towards improving services.

The process below is outlined in *STUDY PROCESS FLOWCHART - See Appendix 3*

Participants & Recruitment

Potential participants will be identified that meet the research inclusion criteria and are currently receiving support from the FLDS. Staff can then distribute the ***Participant Information Leaflet – See Appendix 1*** to the identified potential participants. They will have the option of completing a 'Taking Part' opt-in form to indicate that they are interested in taking part. Staff can then contact Gillian Grieve, the principal researcher to report than an opt-in has been completed. Potential participants will then have a minimum of 7 days to consider their decision to participate and obtain further information if required.

It is planned that after 7 days the principal researcher will check back to confirm whether potential participants wish to participate or not. Those approached do not have to participate and can 1) decide not to participate from the outset or can 2) decide to drop out at any stage during the study without giving reason. Service user's healthcare and legal rights will not be affected.

The principal researcher will arrange to visit those who have completed the 'Taking Part' opt-in form in order to obtain informed consent.

Informed Consent & the Study

During the post opt-in visits those who do wish to participate will then sign a ***Participant Consent Form – See Appendix 2*** agreeing to take part. This shall need to be witnessed by an appropriate member of staff.
Following informed consent, GP's will then be informed of participation in the study. Access to participants HCR-20 forms shall be obtained. It will also be necessary to

access appropriate risk management assessment and protocol information in order to plan for 1:1 participant interviews.

After this information has been gathered, staff and participants will then be contacted in order to schedule the participant interview. Participant interviews shall be conducted by the principal researcher. Interviews shall take place within the Elmwood premises for inpatient participants.

Community patient participant interviews shall take place at an appropriately risk-assessed location such as a communal room within supported-living accommodation. Participant
interviews shall last around 1 hour and shall be audio recorded. Participants shall be asked about their experiences of receiving support from a specialist FLDS.

Potential Benefits to Participants: There is no direct benefit in participation in this study. However, information from this study could assist in improving services.
Potential Risks to Participants: There are no known risks in participation in this study.

Information Sharing
Information obtained during the interviews shall not be shared unless a participant was to disclose information relating to harming themselves or others. This information would then be shared with the Dr. Amanda McKenzie as the project clinical supervisor and appropriate staff supporting that participant.

Following participant interviews the tapes will be transcribed and audio recording will be deleted. All study information will be stored securely. Information relating to the study may be shared with professionals from the University of Edinburgh/ NHS Grampian.

Feedback to Participants
Following the study participants will be given another information sheet that will summarise the general results of the study.

Study Results
The study information will be stored securely for 5 years. The results will be written up as a formal thesis submitted to the University of Edinburgh. The results of the study may also be published and disseminated via talks and conferences.

Study Organisation & Ethical Review
This study is being completed in part fulfilment of the degree of doctorate in Clinical Psychology at the University of Edinburgh. The study proposal has been reviewed and favourable ethical opinion has been obtained from North of Scotland REC Committee.

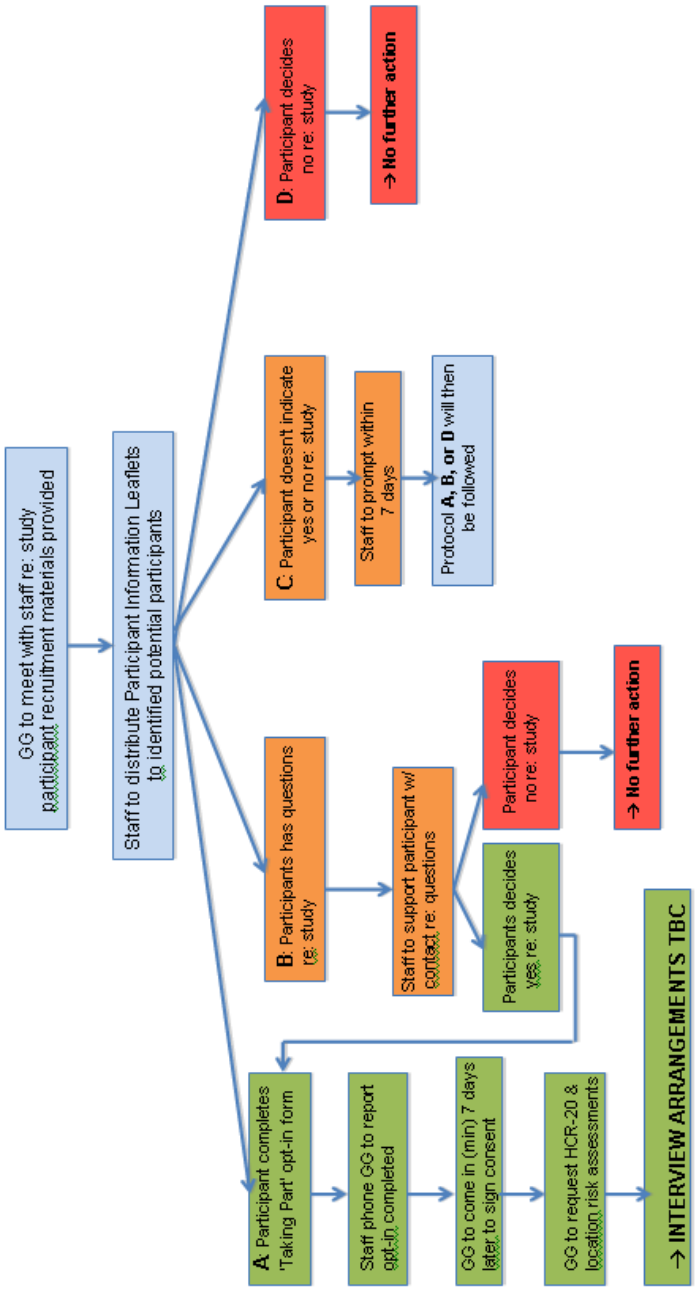
If you have any questions or concerns about this information please do not hesitate to contact:

Gillian Grieve, Trainee Clinical Psychologist c/o Forensic Learning Disabilities Service, Elmwood, Ashgrove Road, Aberdeen, AB25 3BW
Telephone: 01224 557152 Email: gillian.grieve@nhs.net

If you want to make a complaint or support a participant to make a complaint about this study please contact: NHS Grampian Feedback Service, Summerfield House, 2 Eday Road, Aberdeen, AB15 6RE
Tel: 0845 337 6338 Email: nhsgrampian.feedback@nhs.net

Thank you for taking the time to read this information sheet.

APPENDIX 3: STUDY PROCESS FLOWCHART



APPENDIX 7: SAFETY PROTOCOL

REC: 13/NS/0122 R&D: 2013PC009
IRAS: 128190 Version Number & Date: 2 – 07.05.13
Project: *Exploring the experiences of service users in a specialist Forensic Learning Disability Service.*
Principal Researcher: *Gillian Grieve, Trainee Clinical Psychologist*

SAFETY PROTOCOL FOR PARTICIPANT INTERVIEWS

PART 1) General risk procedures to be adhered to during 1:1 participant interviews

N.B. These procedures are consistent with the lone-worker NHS Grampian policies adhered to within the proposed research setting. All interviews shall be completed during routine NHS staff working hours.

A) IN-PATIENT PARTICIPANT PROTOCOL
Prior to interview:
• The principal researcher will obtain a general overview of any relevant risk information and copies of the environmental risk assessments and emergency risk management procedures through consultation with Dr. Amanda McKenzie, Clinical Supervisor of the project.
• The researcher will make 1) The Charge Nurse on duty within the proposed research setting (for in-patient participant interviews) or the Team Leader of the community project (for out-patient participant interviews) and 2) the departmental secretary aware of:
- The interview room location, which will be in a location already risk assessed as suitable for conducting forensic interviews
- The participant being interviewed
- The intended start time and length of interview
- An agreed time at which the principal researcher will make contact and 'check in' with ward staff/community support staff and the departmental secretary post-interview
- That the principal researcher has signed out a Pinpoint alarm for interviews and what number the alarm is and that the principal researcher has received training on how to operate the alarm. When the top half of the alarm is separated from the bottom, a loud alarm sounds which is also sounded within the adjacent buildings in order to ensure an adequate number of staff members are able to immediately attend the interview room
- Arrangements for escorting the in-patient participant between premises if necessary, according to their individual risk management plan.
• The principal researcher will have undergone NHS Grampian 5 day Management of Violence & Aggression training prior to conducting interviews. This will incorporate de-escalation, breakaway and physical intervention techniques.
• The principal researcher will have conducted an environmental risk assessment of the room prior to bringing in the participant and will adhere to NHS Grampian policies in this regard, for example, sitting beside exit door and participant being interviewed behind a desk.

During interview:
• At the beginning of the session, the principal researcher will outline the following information to the in-patient participant:

- The principal researcher is carrying a Pinpoint alarm
- Ward staff members are within a reasonable distance from the interview room and will be immediately alerted should the alarm be activated.
→ Should the principal researcher feel threatened in any way during the interview, they will immediately activate the Pinpoint alarm.
→ Should the personal alarm be activated a number of hospital based staff members shall immediately enter the interview room
→ If the alarm has been activated in error the interview shall continue as before

→ If there is a potential risk or threat to the safety of the principal researcher, responding staff members will then contain the risk by adherence to NHS Grampian management of violence incidents policies.
N.B. Should the pinpoint alarm fail for any reason, the principal researcher would dial an internal number within an NHS Grampian site and directly to a clinical emergency team out with an NHS Grampian site for a clinical emergency.

Following interview:
• The principal researcher will then advise 1) Charge Nurse and 2) the departmental secretary that the interview has been completed.
• Should the principal researcher fail to make contact within 15 minutes of the agreed 'check in' time the departmental secretary/ ward staff members will then:
→ Go to the interview room in order to check the progress of the interview.
→ Should they be unable to gain access to the interview room for any reason, or are unable to confirm
the safety of the principal researcher and the in-patient participant, ward staff will then act according to
NHS Grampian lone working and clinical emergency policies.

B) COMMUNITY PATIENT (OUTPATIENT) PARTICIPANT PROTOCOL:
The location of community interviews shall be dependent upon the needs and management risks of each individual participant. A small proportion of community participants may attend the proposed research setting. In these circumstances the same in-patient participant safety protocol would be applicable, except that the member of support staff accompanying them would be advised rather than the ward Charge Nurse. In the case of community patient participants interviewed within their supported accommodation services the following safety protocol would be adhered to.

Prior to interview:
• The principal researcher will obtain copies of the environmental risk assessments and emergency risk management procedures through liaison with managerial staff at supported accommodation services. These environmental risk assessments will then be shared and discussed with Dr. Amanda McKenzie, Clinical Supervisor of the project.
• The researcher will make 1) The Charge Nurse on duty within the proposed research setting and the Team Leader of the community project and 2) the departmental secretary aware of:
- The interview room location, which will be in a location already risk assessed as suitable for conducting forensic interviews
- The participant being interviewed

- The intended start time and length of interview
- An agreed time at which the principal researcher will make contact and 'check in' with ward staff/community support staff and the departmental secretary post-interview
- That the principal researcher will have access to a Smart-tech personal alarm fob and what number the alarm is, and that the principal researcher has received training on how to operate the alarm. When the top half of the alarm is separated from the bottom, a loud alarm sounds which is also sounded within the adjacent buildings in order to ensure an adequate number of staff members are able to immediately attend the interview room
- Arrangements for escorting the community participant between rooms/ premises if necessary, according to their individual risk management plan.
• The principal researcher will have undergone NHS Grampian 5 day Management of Violence & Aggression training prior to conducting interviews. This will incorporate de-escalation, breakaway and physical intervention techniques.
• The principal researcher will have conducted an environmental risk assessment of the room prior to bringing in the participant and will adhere to NHS Grampian policies in this regard, for example, sitting beside exit door and participant being interviewed behind a desk.

• In line with the Lone Worker telephone system employed within NHS Grampian, immediately prior to interview, the principal researcher will provide the following information to either the departmental secretary or a colleague within the Forensic Learning Disability Service:
- The full address of the interview location
- The participant being interviewed
- The date of the interview
- The intended start time and length of interview
- A synopsis of any known risk concerns about the participant being interviewed which may have relevance to the safety of the principal researcher, for example, if the participant is on the Sex Offender's Register or is known to have committed offences against victims similar in profile to the principal researcher
- A mobile number on which they can be contacted directly
- The participant's home phone number, staff flat number, staff member mobile number
- An agreed time when the principal researcher will phone secretary/colleague post-interview.
• The principal researcher will ensure that they have signed out a Smart-tech fob and are carrying a personal alarm (provided by NHS Grampian).
• The principal researcher will ensure that they have checked with the Team Leader what the participant's supervision levels are, for example, do they require 2:1 staffing and no lone working
The principal researcher will have completed a Buddy System form which will be held by the departmental secretary and be counter-signed by Dr McKenzie. This will ensure that the principal researcher's personal details, including car registration, is stored confidentially and easily accessible.

During interview:
• At the beginning of the session, the principal researcher will meet with both the community staff member and the participant in order to make the community patient participant aware that the principal researcher is equipped with a personal alarm and Smart-tech fob and to agree the following:
- the community staff member will stay within a reasonable distance from the interview room in order to ensure they are able to respond to the Smart-tech fob alert, should it be activated.
→ Should the principal researcher feel threatened in any way during the interview, they will immediately activate the Smart-tech fob.

→ Should the Smart-tech fob be activated the community staff member shall immediately enter the interview room.
→ If the alarm has been activated in error the interview shall continue as before.
→ If there is a potential risk or threat to the safety of the principal researcher the community staff member will then set in motion their own organisation's emergency risk management procedures.

Following interview:
• The principal researcher will then call the secretary/colleague immediately/ at the agreed time
• Should the principal researcher fail to make contact within 15 minutes of the agreed time the secretary/colleague will then:
→ Attempt to phone the principal researcher's direct mobile number.
→ Should there be no answer, they will then attempt to telephone the participant's home phone number, staff flat number, staff member mobile number, and will ask to speak directly to the principal researcher.
→ If there is no answer/ or they are unable to speak with the principal researcher they will then attempt to call the principal researcher's direct mobile number a second time.
→ If no answer is received they will then telephone the police immediately to advise them of the situation.

PART 2) Disclosure of intent to harm procedures to be adhered to during 1:1 participant interviews

N.B. The procedures outlined are consistent with the lone-worker NHS Grampian policies adhered to within the proposed research setting service.

During interview:
• Following discussion of the general risk procedures protocol outlined above. Prior to administration of the interview questions the principal researcher will advise the participant of the following:

- '*During this interview, if you tell me something about harming others (which I don't know already), or about someone harming you (which I don't know already), or about you wanting to harm yourself or any other illegal activities - I must pass this information on to another staff member, such as your psychologist/ psychiatrist/ and possibly your GP'*.

- The principal researcher will then ask the client to summarise the information provided in their own words in order to ensure comprehension.
→ Should a disclosure of this nature occur during the interview the following protocol will be followed:
→ The interview will be stopped temporarily.
→ The principal researcher will explain to the participant that they have provided information which must be passed on as discussed prior to the administration of the interview questions.
→ Should the participant wish to continue with the interview at a future date this can be arranged in consultation with the project Clinical Supervisor, staff and the participant.
Following interview:
→ The information disclosed during interview will then be passed onto the Clinical Supervisor of the project in the first instance, and then onto any other relevant parties such as psychiatry

colleagues or participant's GPs thereafter. The parties informed shall be dependent upon the nature of the disclosure, this decision shall be guided by the Clinical Supervisor. If a disclosure of self-injurious behavior is made the duty psychiatrist and GP will be contacted in the first instance. If a disclosure of intent to harm others the principal researcher will need to contact the police, following supervision with the project Clinical Supervisor.

APPENDIX 8: DISTRESS PROTOCOL

REC: 13/NS/0122 R&D: 2013PC009
IRAS: 128190 Version Number & Date: 4 – 23.04.14
Project: *Exploring the experiences of service users in a specialist Forensic Learning Disability Service.*
Principal Researcher: *Gillian Grieve, Trainee Clinical Psychologist*

NHS Grampian

DISTRESS PROTOCOL FOR PARTICIPANT INTERVIEWS

N.B. This protocol shall be followed during both inpatient and community (outpatient) participant interviews.

In the case of distress during interview the following protocol will be implemented:

→ Should the participant become distressed in any way during interview they will be asked if they would like a break or if they would like the interview to be terminated. If they indicate the latter the researcher will immediately stop the recording and terminate the interview.

→ The principal researcher will then ask the participant if they would like a ward staff/ community staff member to come into the interview room to join them or if they would want a staff member to assist them in contacting someone else on their behalf e.g. a named nurse, advocacy worker etc.

→ The principal researcher will then check if the participant wishes to leave, or wishes them to leave (depending on the interview venue). The principal researcher will then leave/the participant will leave but the principal researcher will ensure that a member of staff is present when this happens.

→ The principal researcher will encourage the participant to speak to his/her own psychologist/ psychiatrist in the first instance and will facilitate contact where appropriate.

→ The principal researcher will also offer a list of helpline numbers (Breathing Space and Samaritans) where appropriate, for example in the case that the participant does not wish to speak to anyone else at that time – *See Helpline List for Participants Version 3 - 14.06.13.*

→ Following this, staff and client will be reminded that information regarding placing a formal complaint about the research study and how it is conducted is available within the initial information provided during recruitment – *See Participant Information Leaflet Version 8 – 22.04.14 and Staff Information Sheet Version 5 -22.04.14.*

Helplines for Support

If you are feeling upset you can get support from:

SAMARITANS	**Samaritans** This charity gives support to people who are feeling upset or feeling suicidal. Telephone: 08457 90 90 90 (you can phone anytime day/night) Email: jo@samaritans.org Website: www.samaritans.org
BREATHING SPACE	**Breathing Space** This is a charity that gives support to people who are upset, sad or feeling suicidal. Telephone: 0800 83 85 87 (you can phone between Mon-Thurs 6pm-2am, and Fri - Mon 6pm-6am) Website: www.breathingspacescotland.co.uk

You can also speak with your psychologist or psychiatrist.

REC: 13/NS/0122 R&D: 2013PC009
IRAS: 128190 Version Number & Date: PIL 8 – 22.04.14
Project: *Exploring the experiences of service users in a specialist Forensic Learning Disability Service.*
Principal Researcher: *Gillian Grieve, Trainee Clinical Psychologist*

Participant Information Leaflet

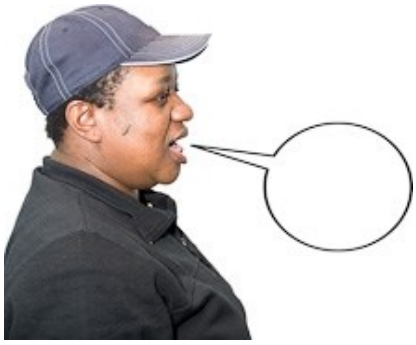
	I am Gillian Grieve. I am training to be a Clinical Psychologist. I study at Edinburgh University and work for NHS Grampian. I am doing a research study. I would like to ask you to take part in the research study.
	This study is about support from the Forensic Learning Disability Service. This could help us to make the service better.
	You do not have to take part. You can say yes or no. This will not change the support you get from the service.

If you want to take part - fill in the **Taking Part Form**.

I will visit you to tell you about the study.
I will ask you to sign a **Consent Form**.

I will write to your GP or Psychiatrist and tell them you are taking part.

I will read your patient notes.

	We will have 1 meeting. We will meet for 1 hour. Staff will plan where this meeting will be.
	I will ask you about the support you get. It is ok if you do not want to answer all the questions. You can stop at any time.
	If you tell me anything about harming yourself or others, or any illegal activities, I have to tell staff. This is to make sure everyone is safe.
	I will record what you tell me on a tape. I will type this up on a computer. I will not tell anyone your name or any personal information. This means no one will know who you are.

	I will write to tell you about the study when it is all finished.
	I will write a report for Edinburgh University and journals. The report may be published or shared with other staff.
	I will keep the notes and tapes in a safe place. Only the study staff will see them. Other people will not know your name or any personal information.

Study Contacts

	If you want to know more about the study, talk to staff or you can: Contact me: Gillian Grieve Trainee Clinical Psychologist Telephone: 01224 557 142

	Contact my supervisor: Dr Amanda McKenzie Principal Clinical Psychologist Telephone: 01224 557 142

	Contact a learning disability staff member who is not part of the study: Sheila Dalziel Community Nurse Telephone: 01224 558 313

If you want to make a complaint about this study you can contact:
NHS Grampian Feedback Service, Summerfield House, 2 Eday Road, Aberdeen AB15 6RE Telephone: 0845 337 6338.

Taking Part Form

Tick the red boxes below then give this form to staff.

	I want to take part in the study.	☐
	It is ok for Gillian Grieve to come and talk to me about the study.	☐

Name: _____ Signature: _____

Staff name: _____ Staff Signature: _____

Staff phone number: _____

Date: _____

REC: 13/NS/0122 R&D: 2013PC009
IRAS: 128190 Version Number & Date: PCF 8 – 25.04.14
Project: *Exploring the experiences of service users in a specialist Forensic Learning Disability Service.*
Principal Researcher: *Gillian Grieve, Trainee Clinical Psychologist*

NHS Grampian

Participant Consent Form

Write your initials in the red boxes below

	I have read the Participant Information Leaflet.	
	I have had time to think about taking part.	
	I have been able to talk to someone about the study.	

I know I do not have to take part. I can stop any time.

I know study staff will read my patient notes.

I know study staff will record what I say.

I know staff will keep my notes and tapes in a safe place.

	I know study staff will tell my GP I am taking part.	☐

	I agree to take part.	☐

Sign your name below

Name	Sign	Date
_____	_____	_____
Name of Witness	*Signature*	*Date*
_____	_____	_____
Name of Principal Researcher	*Signature*	*Date*

N.B. 1 copy for:
A) Participant
B) Participants Clinical Notes
C) Secure Project Site File

APPENDIX 11: SEMI-STRUCTURED INTERVIEW SCHEDULE

REC: 13/NS/0122 R&D: 2013PC009
IRAS: 128190 Version Number & Date: 5 – 22.04.14
Project: *Exploring the experiences of service users in a specialist Forensic Learning Disability Service.*
Principal Researcher: *Gillian Grieve, Trainee Clinical Psychologist*

DRAFT SEMI-STRUCTURED INTERVIEW SCHEDULE

Topic A: Exploration of Forensic Learning Disability Service Support
Question 1 (General Descriptive Opening Question): Can you please tell me a bit about where you are living at the moment?
Prompt (if requiring clarification of current service vs. location): prompt re: service provider/ inpatient ward etc.

Question 2 (General Narrative Question): Tell me how you came to be supported by the Forensic Learning Disability Service?
Photo Prompt (if requiring clarification of current service): photo of the service building.

Topic B: Forensic Learning Disability Transition & Input
Question 3 (Comparative to past circumstances Question): Can you tell me a bit about where you were before this?
Prompt (if requiring clarification prior to transition) prompt re: when you were an inpatient/ when you were a community/ outpatient?

Question 4 (Narrative Question): Can you tell me a bit about your move from inpatient to community/ outpatient services?

Question 5 (Structural Question): Can you tell me what were all the stages in planning this transition/ move?
Prompt (if requiring concrete support) can draw this out with participant) (Timeline?)

Question 6 (Evaluative Question): How do you feel about this transition/ move?
Photo Prompt (if requiring support in identifying emotions) provide photo symbols prompts

Question 7 (Comparative to past circumstances Question): Did you feel like that before?
Photo Prompt point to previously identified emotion if previous prompt required.

Question 8 (Evaluative Question): Was there anything (what was) good/easy about the transition/ move?
Photo Prompt photo symbol to represent easy/ good/ positive connotations.

Question 9 (Evaluative Question): Was there anything (what was) bad/hard about the transition/ move?
Photo Prompt photo symbol to represent hard/ challenging/ negative connotations.

List of other potential questions/ topics of exploration (NOT REQUIRED)
Tell me some good things about getting support from this kind of service?
Tell me some difficult things about getting support from this kind of service?
Tell me about a time when the support was good/ useful?
Tell me about a time when the support was not good/ not useful?

APPENDIX 12: DISTRIBUTION OF THEMES ACROSS PARTICIPANTS

Master themes	Super-ordinate Themes	P001	P002	P003	P004	P005	P006	P007	TOTAL
1. RELATIONSHIPS WITH STAFF	Containing: staff as supporters	✓	✓	✓	✓		✓	✓	6/7
	Restraining: staff as supervisors	✓	✓	✓	✓	✓	✓	✓	7/7
	Issues of trust		✓	✓	✓			✓	4/7
2. LIVED EXPERIENCE OF TRANSITION	Emotional responses to change	✓	✓	✓	✓	✓	✓	✓	7/7
	Powerlessness: lack of inclusion, choice and information	✓	✓	✓	✓	✓	✓	✓	7/7
	Importance of steps between	✓	✓	✓	✓	✓		✓	6/7
	Adapting to the new	✓	✓	✓	✓	✓		✓	6/7
	Missing the old	✓	✓	✓	✓		✓		5/7
3. STEPS TOWARDS FREEDOM	Increased control and autonomy	✓	✓	✓	✓	✓	✓	✓	7/7
	Increased privacy		✓		✓	✓		✓	4/7
	Remaining restrictions			✓	✓	✓		✓	4/7
4. COMMUNITY EMBEDEDNESS	Work and meaningful activity	✓	✓		✓	✓	✓	✓	6/7
	Relationships with others	✓	✓	✓	✓	✓	✓	✓	7/7
	Establishing a '*home*'	✓	✓		✓		✓	✓	5/7
5. DIFFERENT CONCEPTS OF SELF	Self as forensic service user	✓	✓	✓	✓	✓	✓	✓	7/7
	Forging new identities		✓	✓		✓	✓	✓	5/7